Spring 2023 | Issue 69 | Price where sold: £6.25

Colostomy UK

AWARD-WINNING

Tidings

Supporting & empowering ostomates

Working with British Airways to ensure travel is accessible for YOU

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There Should be Unicorns

Real stories
Real people

Colostomy UK

Your Loose change has BIG impact

Has Tidings helped and supported you during your time of need?

Did you know that each issue costs us £6.25 to produce, that's £25 a year for each reader.

Can you donate £25 to Colostomy UK so that someone else in need gets the same support you did?

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Debit or credit card: visit **www.colostomyuk.org/donate** or call us on **0118 939 1537**.

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Colostomy UK

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Tidings

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PAGE 6

BETTER BA

LET'S RISE TO THE CHALLENGE TOGETHER

Thank you for your support.

Colostomy UK

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Dear readers

A happy new year to all our readers. As I write this I'm staring out at a gloomy grey sky and wishing it was summer! Hopefully though, as you read this, the first signs of spring will be in evidence.

Before giving you an outline of what lies ahead in this Tidings, I thought I would begin by mentioning the dreaded 'P' word – prescriptions. Some of you may have personally experienced or read about other ostomates who have recently had problems accessing their normal prescription stoma products from their supplier. With this in mind, you will find a short guide on pages 18-19, explaining your rights as an NHS patient in England with intimate healthcare needs. If you live in Scotland, then you can access similar information from the NHS Inform website. Those of you in Northern Ireland should visit www.nidirect.gov.uk and people in Wales www.gov.wales.

There should be something of interest for everyone in this edition. Rather than Dear Nurse, we have Dear Consultant, with our president Ian Daniels FRCS (who is a consultant Colorectal and General Surgeon) contributing a short but important piece about colonoscopy through the stoma. We know that this causes anxiety, particularly with people who haven't had one before. Ian's article appears alongside one from a patient, talking about their experience of the procedure. Hopefully the two combined will ease people's worries. Staying with healthcare professionals, on pages 21-23 Michelle Boucher who is a stoma care clinical nurse specialist in Salisbury reports on research she conducted for her PhD, looking at colostomy as an early active choice in bowel management for people with spinal injuries. I found it a particularly interesting piece as some of her findings echoed the experiences of Dave Thraves, a spinal injury patient, whose story we covered a while back (Tidings winter 2020).

We have three very different Real Lives stories. Lucy Clive, who until recently was running her own food business, explains how having an emergency stoma gave her the inspiration to write her own 'stoma-friendly' cookery book. She has also contributed a seasonal recipe for you budding cooks out there. Steve Arnott also had emergency stoma surgery. We trace his stoma journey and how it has ultimately led to him using his public profile to raise awareness about stomas and champion the needs of people with them. And last but not least, Louise Turner who is an assistant practitioner with Fittleworth Medical Ltd, talks about her work in the community and how this has involved providing stoma care to a man with Down's Syndrome.

To round things off, you will also find inside all the latest news from Colostomy UK, support groups around the country and a thought-provoking article from our volunteer, David Christian, who describes how patients have played a central role in the development of stoma care in the East Kent region.

Best wishes,

Richard

Richard Biddle
Editor, Writer & Researcher

Colostomy UK

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

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

How to contact us

Stoma helpline for:

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

Adminline for:

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

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

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0118 939 1537
Giovanni Cinque
GetInvolved@ColostomyUK.org

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

WWW.**COLOSTOMYUK**.ORG

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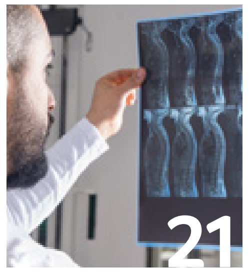
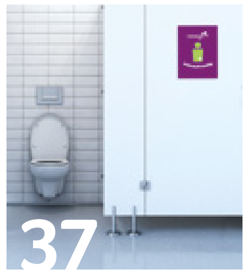




Colostomy UK News

Real Lives

Wellbeing

Support

Donating to Colostomy UK

An annual donation of £25 (or what you can afford) allows us to produce Tidings and to continue our vital work, supporting, and empowering ostomates – see page 39 for our donation form.

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

news

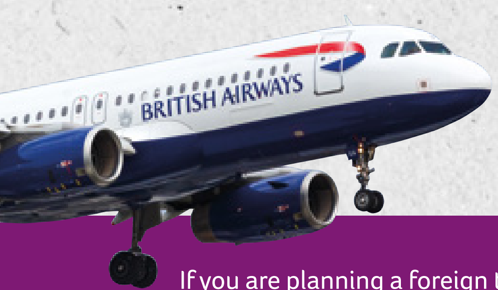
Libby Herbert
CEO
Libby.Herbert@ColostomyUK.org

British Airways Stoma Education Workshop

We know air travel figures prominently in many people's minds. Every year our Stoma Helpline receives enquiries from people about to go abroad for the first time since their surgery. Our Travel Booklet and Travel Certificate continue to be popular.

Regular readers will also know that over the years we have devoted considerable resources to engaging directly with the aviation industry, advocating on behalf of people with stomas. Our work here is multi-faceted. As members of a number of airport accessibility forums and with me sitting on the Civil Aviation's Access to Travel panel, we have been able to influence and advise on everything from security procedures and policy to airport signage and toilet facilities. In fact, where airports are concerned, we have become the 'go to' stoma charity; we are currently working with the following: Gatwick, Heathrow, Stansted, Cardiff, Manchester, Birmingham, Luton, Cornwall and Bristol.

The pandemic had serious implications for aviation and saw many airport staff laid off. Thankfully things are now returning to normal, and the industry is gearing itself up for a busy 2023. We were therefore delighted to be asked by British Airways (BA) to deliver a series of Stoma Education Workshops to their Accessibility Team, as pictured on the front cover of this edition. This team is dedicated to supporting people who might have additional needs in order to feel safe and confident when travelling (be it at the airport, flying, or both).



The workshops were delivered in Newcastle by me and Bobbie Minshull, one of our long-standing volunteers. We explained what a stoma is, why people have stoma surgery and gave participants an understanding of the practical and emotional needs that someone with a stoma might have when they travel by air. We also gave attendees a broader appreciation of Colostomy UK and the work we do. The Q&A session was popular. But Bobbie stole the show. As someone with a colostomy, urostomy and a fistula, she was able to bring alive the experience of traveling as an ostomate and all the concerns this can encompass from the need for extra hand luggage, to worries about body scanners and being searched, to the importance of staying hydrated and needing things like an aisle seat on the plane in close proximity to the toilets. Post-workshop feedback was positive. Tracy Armstrong, Business Manager in BA's Servicing, Accessibility and Refunds, described it as 'informative' and 'thought provoking' and said that after attending, her team had been more confident assisting people with stomas. Indeed, this led to one ostomate saying: "Well done BA you've given me the confidence to fly again."

If you are planning a foreign trip, then visit our website for the latest updates and don't forget to request or download our Travel Advice booklet and Travel Certificate. You could call the Stoma Helpline too and speak to one of our volunteers experienced in air travel. We also recommend that when you make a travel booking you tell the agent of your additional travel needs and/or contact your airline and the airport you will be departing from. The latter should be done well in advance of travelling (at least 48 hours before) to sort out things like extra hand luggage allowance, as you might be asked to provide supporting documentation, such as a letter from your GP.

Supporting and empowering you
Colostomy UK
Travel Advice
Having a colostomy should not prevent you from travelling at home or abroad
0800 328 4257
24/7

The Scottish Stoma Forum (SSF)

SSF was formed in 2007 to ensure the services provided to Scottish stoma patients are maintained at the highest possible level. The Forum's members include us, the UA and the IA, specialist nurses, surgeons, manufacturers, and suppliers of stoma appliances.

The SSF would like to better understand and prioritise the needs of patients living with or awaiting stoma surgery in SCOTLAND.

The SSF have partnered with CFEP UK Surveys to do this and would like you to take a moment to share your views as a person with a stoma who lives in Scotland.

So far, they have received 900 responses. According to the British Health Trade Association there are 18,000 people in Scotland with a stoma. It would be great if we could get more responses to this survey.

All responses are anonymous and a summary of the findings of the survey will be published at the end of 2023.

Please select a suitable answer for each question by clicking on the relevant option. If you are unable to answer a question, please leave it blank. When you have completed this survey click on the 'Send' button located at the bottom of the survey to submit your answers.

This survey must be completed in one session and may only be submitted once. It will only take about 10 minutes to complete, and it is mobile friendly.

To get started please visit: https://cfep.net/19nPNR or scan this QR code.

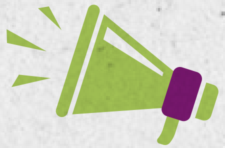
Active Ostomates classes in the community

Pilates, Yoga, and Art are amongst the classes that support group members in Dartford, Chatham, Windsor, and Salisbury will be able to participate in during the coming months.

Additionally, as well as virtual classes, we are now pleased to announce that we are once again able to offer them face-to-face.

If you run a support group and are interested in hosting one of our free classes, please email **GetInvolved@ColostomyUK.org**.

Congratulations to the winners of our 2022 prize draw



1st prize £2,500
» Rowland Shallcross

2nd prize £1,000
» Zoe Wiggins

3rd prize £100 x 10
» Robert from Littlehampton
» Ingrid Bowden from Lostwithiel, Cornwall
» Mrs Kay from Devon
» Doug Low from Brechin
» Terry Dineen from Crumlin, Northern Ireland
» Marian from Chorley, Lancashire
» Mary Le Coyte from Dulverton, Somerset
» Gilbert from Scarborough
» Mr Bird from Scarborough

Colostomy UK Walking Football in Surrey

On 6 May in partnership with the Surrey Football Association and Hollister, we'll be launching our new weekly free walking football sessions.

They will take place at **Goals Sutton, 656 London Rd, Sutton SM3 9BZ from 1.30-2.30pm.**

Sessions are open to people of all ages and genders, and you can bring a friend or family member along too, so if you live in Surrey or the surrounding counties and would like to register or find out more, please email **GetInvolved@ColostomyUK.org**.

Colostomy UK

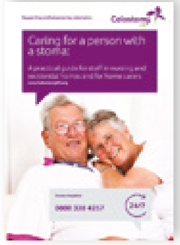
Literature range

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

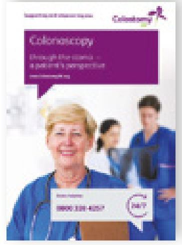
Admin line: 0118 939 1537 | **Email:** hello@ColostomyUK.org | **Website:** ColostomyUK.org/information


Active Ostomates sport and fitness after stoma surgery


Campaigns and Projects Flyer


Caring for a person with a stoma


Caring for a person with a stoma and dementia

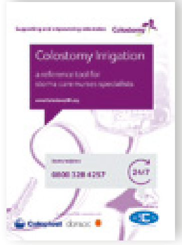

Colonoscopy through a stoma


Fundraising Pack


Healthy Eating

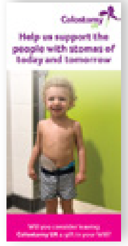

Helpline Cards

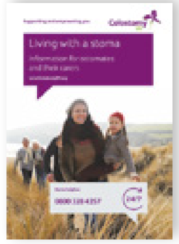

How will a stoma affect me?

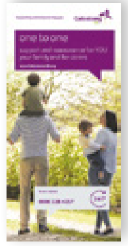

Irrigation Booklet


Irrigation DVD (nurses)


Irrigation DVD (patients)

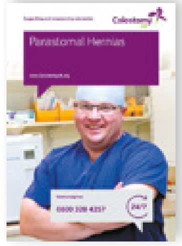

Legacy Flyer


Living with a stoma

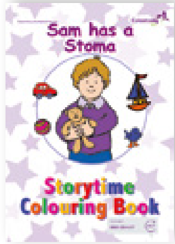

One to one


Ovarian Cancer and stomas


Pain and discomfort

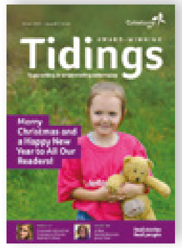

Parastomal hernias


Rectal discharge


'Sam has a stoma' colouring book

Stoma friendly toilet guideline and stickers

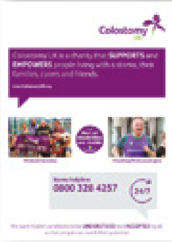

Stoma reversal


Tidings magazine


Travel advice


Travel certificate


Tri-Charity leaflet


Welcome pack

Lucy's Gastronomic Journey

BY RICHARD BIDDLE

The connection between diet and health has been long appreciated. If you had been ill back in Hippocrates time (born c. 460 BC) and had visited a physician, then the chances are his cure would have included dietary advice. For a winter sniffle, he might have suggested ginger believing its 'hot' qualities would counteract your cold. In the mid-nineteenth century the German philosopher Ludwig Feuerbach declared: 'we are what we eat', not knowing this phrase would still be popular two centuries later. Today, the government advises us to eat 'five-a-day'.

On TV, diets and dieting feature heavily, as do commercials for companies that for a monthly subscription will deliver parcels of perfectly balanced food to your door. But eating well is not necessarily straight forward when you have a stoma. While some ostomates are lucky enough to be able to eat what they want, others experience problems with certain types of food. This is why we produce our healthy eating booklet and in Tidings feature articles from dietitians, such as Pooja Dhir (Tidings winter 2022).

Knowing how important diet is and what a bugbear it can be for some ostomates I thought readers would find Lucy Clive's story interesting - not just because it covers her struggles with food and diverticulitis, but also because until recently, she ran a successful food business.

Having had a stoma for almost a year before it was reversed, Lucy has recently turned her culinary skills to writing a 'stoma-friendly' recipe book. At the end of this article you will find one of her recipes, which uses seasonal vegetables. When I asked Pooja to cast her professional eye over it, she said it was great from a nutritional perspective as the variety of vegetables support fibre intake, vitamins and minerals, and the 5-a-day fruit and vegetables daily guidelines. She also commented that the recipe provided flexibility to swap the vegetables for others you prefer and blending down the vegetables would make them easier to tolerate if your stoma is more active.

Lucy is 47 years old and lives in Worcestershire with her husband Rich and teenage daughter Ava. The family are keen tennis players, although Lucy admits she is content to let Rich and Ava play doubles if this means she gets an uninterrupted Sunday afternoon in her kitchen. Lucy's love of cooking goes back to when she was little and owes much to her mother, who was a classically trained cook. The two of them would spend hours together working through recipes, with Lucy tasting and learning as she went. It was her mother who taught her how to do everything from making a roux to julienning vegetables. At age 14 Lucy had a Saturday job in a local restaurant and by the time she started her own business in 2009 creating, making and serving soups, she had been a pot wash in Glasgow, managed cafés and restaurants in London, Leeds and Edinburgh and done three seasons of catering as ski chalets in the French Alps.

Lucy was diagnosed with Diverticulitis in 2010. She remembers the doctor telling her to:

> **"work out your trigger food and control it, or we will see you back here needing surgery."**

By this point Lucy already had suspicions that red meat was behind her flare-ups and so cut meat out of her diet altogether. Given Lucy's position as chief cook, the rest of the family went vegetarian too (although she did take pity on Rich and do him the occasional steak!). Lucy started to cook a lot more fish and became an expert creating veggie curry. Initially she was excited to experiment with new ingredients and recipes, but she missed a good chicken roast and still craved the broth she made with the leftovers. As the years passed and with them the memories of her illness, Lucy gave in and reintroduced meat to the family menu.

As you have probably guessed, this didn't go well. Just before the country went into lockdown Lucy was back seeing her GP. The old familiar pain in her tummy had returned, she was feeling anxious and knew something was wrong. Her doctor told her to do more exercise and cut down on alcohol. The advice, though sound, took no account of how things were about to change. As we know, Covid restrictions weren't particularly conducive to doing more exercise or cutting back on the sauce, quite the opposite in fact. Like everyone else, Lucy and her family passed evenings doing their best to keep in touch with people via Zoom get-togethers. Rather than addressing her pain, Lucy learned to live with it. But she couldn't shake how she was feeling mentally. In fact, matters started to get worse, forcing Rich to keep out of her way. Lucy remembers feeling like she was sinking and, having run a successful business for 13 years and raised her daughter, found she was now struggling with the demands of everyday life.

As restrictions lessened, Lucy was able to re-start her business and cater again for cafés and private functions. But then, in the spring of 2021, while preparing the food for the 'finals' at the local tennis club, she experienced sudden and terrible pain. Within 48 hours she was having surgery, by the end of which she had no appendix, ovaries or fallopian tubes, had lost a large section of colon and gained a stoma. It turned out that her bowel had perforated, and she had abscesses throughout her pelvic floor and bowel. She was lucky to be alive. Lucy left hospital five weeks later, after passing what her doctor called her 'stoma diploma'. This involved doing a bag change on her own. Like many people who have stomas (emergency or planned) Lucy found the whole thing an ordeal.

Post-operatively, as Lucy recovered, she vowed to make happen the recipe book she had had in her head for many years. Ever since running her business she had been learning to adapt recipes to account for her customers' allergies and intolerances. Before she left hospital Lucy's stoma nurse talked to her about foods that can cause blockages, such as nuts and popcorn and foods to avoid on account of their capacity for causing wind (garlic, leeks, lentils). She then handed her a leaflet about diet in the early days as an ostomate. To Lucy, this pep talk and the leaflet were like throwing down the gauntlet. With her culinary background she thought: 'I've got this'… but this was before she realised just how differently her body was going to react to food.

As a consequence, her recipe book has undergone revisions! Lucy freely admits that she is not very good at being told 'no'. Early on she waded in with mushrooms on toast, only to discover that the mushrooms came out exactly the same way they went in. Her body wasn't able to break them down and absorb the goodness in them. She also wrongly assumed that it was the shape of nuts that caused blockages, not appreciating that nuts absorb moisture in the bowel and that it is this that usually causes the problems. Lucy found this out after scoffing a big batch of spicy winter nuts that she made for a family outing to the seaside. She was also alarmed at the rapid results produced by her early attempts at curry (the first being sweet potato and chickpea). From this she learned to go more fragrant than spicy, to make the curry drier and increase the rice to curry ratio. It's been a gastronomic journey for Lucy during which she has learned from trial and error and from reading about other ostomates' experiences with food. She hopes to have captured all this knowledge in her recipe book. When we spoke, she was still in the throws of completing it, but everyone at Colostomy UK wishes her well in the endeavour. Keep an eye out on Amazon and in the meantime enjoy Lucy's recipe.

Pea, courgette, watercress & mint soup

A real treat for your taste buds. Combining the sweet petit pois, the fresh mint and the peppery watercress, with a big dollop of crème fraiche gives this soup a delicious velvety feel.

Ingredients:

- 1 leek including the lovely green top
- 1 small white onion
- 1 glug of olive oil & small knob of butter
- 1 large courgette
- Small bunch of fresh mint or 1 teaspoon of dried mint
- Ground black pepper
- Large handful of watercress
- 300g frozen petit pois
- 500ml of veg stock
- Large spoon of crème fraiche

Method

Start by peeling and chopping your onion. Wash and chop the leek and add with the onion to a big pan with the olive oil and butter. Gently sauté for 5 minutes over a medium heat. Don't let them brown, as this will change the flavour of the onion, which you don't want in this soup.

Now add your courgette after you have washed, topped and tailed it, and roughly chopped. You may need a splash of water at this stage. Cook the courgette over a medium heat allowing it to soften with the onion and leek mix.

Now add your mint leaves, a good grind of black pepper and the watercress with another splash of water. One of the fabulous things about this soup is the colour, so make sure the courgette, leek and watercress mix is soft before you add your peas in. Your peas will only take a few minutes to cook, that way they will keep their vibrant green colour.

Once you are happy that the courgette mix is soft, add the peas and vegetable stock. Bring to the boil and then take off the heat immediately.

Drop in a dollop of crème fraiche and blend your soup. I often use an electric blender. It can take a few extra minutes to get the shells of the peas blended down, but you really want to get your soup very smooth. Now, have a taste and add more salt and pepper if required.

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One piece drainable

Onovus Solo
One piece closed

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*60% ambient noise reduction and 30% noise reduction when rustling, when compared to competitor bags.

**In a 2022 study, 31.7% of participants found that their usual stoma pouch limits the choice of clothes they can wear in comparison to 20% whilst using the Onovus Solo.

***In a 2022 study, Ostique's proprietary baseplate achieved a 97% conformity rate across various types of stomas (including healthy stomas, double-barrel stomas, prolapsed stomas and necrotic stomas), in comparison to Competitor 1 (91% average conformity rate), Competitor 2 (94% average conformity rate) and Competitor 3 (90% average conformity rate), performing significantly better than all other competitor products tested.

ostique

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Ostique's Onovus Solo range brings the first truly 'silent' bags* to market. The ground-breaking pouch material heavily reduces noise levels, is waterproof, dries in seconds and comes in a unique, stylish colour.

Ostique's baseplate utilises a novel, patented adhesive combination which provides improved flexibility, security and comfort.** This can also reduce leakage and improve overall skin health.

Plus, the pouch design ensures ultimate discretion, remaining flatter throughout use than traditional bags***, providing you with the freedom and confidence you've been craving.

But don't just take our word for it...

"I am very impressed as [it is] waterproof which makes it extra good for swimming and showering. It does not rustle, like many others do." - Ostique Onovus Solo User, September 2022

"Loved the bag material - no crinkly sounds, magic!" - Ostique Onovus Solo User, September 2022

"I really prefer the adhesive compared to my current stoma bag. It allowed my skin to breathe more." - Ostique Onovus Solo User, September 2022

"The baseplate felt comfortable and was barely visible on my skin and not at all bulky." - Ostique Onovus Solo User, September 2022

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There Should be Unicorns

BY RICHARD BIDDLE

Steve Arnott's CV is nothing but impressive. It includes being the focus of an award-winning documentary, setting up 'Beats Bus', a not-for-profit social enterprise aimed at empowering the young people of Hull, and, more recently, playing a leading role in a theatre production inspired by his life. But what many people don't realise is that while Steve was achieving all this, he was privately dealing with being very unwell. In 2012 he was diagnosed with diverticular disease and in 2019 he had emergency stoma surgery. He describes the last three years as: 'The Hardest Fight of My Life'. In his battle to come to terms with his stoma, he has gone from self-loathing and pain, to using his public profile to champion the cause of stoma awareness.

Steve setup Beats Bus in 2017. If you are down with the kids, then the name should give you an inkling as to what it is all about. But, as I'm guessing you aren't, I will do my best to explain. In essence Beats Bus is about bringing arts and music to communities that lack such provisions. The Beats Bus is a 7.5 tonne Iveco truck fully equipped with a professional recording studio. Steve and his team use hip-hop to reach the organisations, youth projects and communities they take the bus to. They run workshops on the history of hip-hop and the various elements that comprise hip-hop: song writing; breakdance; graffiti; DJing; and knowledge.

As a consequence of their work, young people have been able to record and perform songs they have written about topics such as racism, society, and the pressures of life.

Although Beats Bus is now thriving, Steve struggled to get his dream off the ground. In the early days both time and money were huge issues. When the Department for Digital, Culture, Media & Sport awarded Hull the title of 'City of Culture' in 2017, Steve hoped this might be the moment when things changed. But alas it wasn't and his application for funding came to nothing, even though he felt Beats Bus ticked every box. Despite the disappointment Steve pressed on. Later that year he met by chance the filmmaker Sean McAllister at a screening of the latter's film 'A Syrian Love Story'. Seizing the opportunity, he told McAllister about Beats Bus and how this was his city of culture dream. The next day McAllister texted him, explaining he was going to be away for a while. Steve thought that was it, he'd hear no more. But this proved not to be the case…

The two agreed to collaborate and the result was the critically acclaimed documentary 'A Northern Soul'. First aired at the Sheffield DocFest in June 2018 and then again in early 2019 on BBC2, this captured Steve's life as he tried to balance full-time work as a warehouseman with trying to get the Beats Bus dream off the ground. The window it provided on the struggles of working-class people in the UK went on to be discussed in the House of Commons, and Northern Soul was even screened in Parliament. It also led to funding for Beats Bus, allowing Steve to quit his job in the factory and focus fulltime on the project.

Steve was obviously thrilled with the reception the documentary received and how it had indirectly furthered the Beats Bus dream. He found it exciting, but also stressful: "I had to financially support a team to follow the dream; taking on the sustainability of the Beats Bus weighed heavily on me." Since his diverticulitis diagnosis in 2012, Steve had been successfully managing his condition through diet. But this was before having to bear his new responsibilities. The toll these were taking became evident in May 2019 following a night out to celebrate the birthday of Beats Bus tutor, Nigel.

It started with stomach pains which became intolerable overnight. These were accompanied by heavy sweats and blood when he went to the toilet. First thing in the morning Steve's partner Yaz took him to a walk-in centre, where the doctor sent him immediately to A&E. At first it was thought his appendix was the problem and he was told he would probably need surgery. A few hours later he was told surgery would not be necessary.

He then went to the toilet and, in Steve's words: "I saw red and thought, 'I'm dead', and just passed out." Rather than an appendicitis, it turned out that Steve's bowel had perforated, and he had sepsis.

Steve was in hospital for 13 days after his surgery. When discharged he was initially buoyant, giving an interview to promote A Northern Soul in Hull Royal Infirmary's car park, and later telling the Hull Daily Mail that although it wasn't uncommon for recovery to take six months, he was aiming for six weeks. As he explained, he was meant to be out touring and had already missed visits to Scotland, Leeds and York. But it wasn't long before a shadow started to fall on Steve's upbeat mood. Reality quickly made its presence felt, as Steve started to confront the physical and mental challenges of having a stoma. As he recalls in a recent blog post: "There was so much to deal with on so many levels: acceptance, self-loathing, pain, unstable mental health and pushing people away who I love."

In the end Steve's six weeks was much longer. It was nearly three years before he was able to openly speak about what had happened to him and what life with a stoma was like.

> Like many ostomates I have spoken to, Steve reached a point in his journey where he decided he needed to grasp life once again.

Steve can't pinpoint exactly what it was that triggered or brought about this defining moment. Either way, the world has looked a different place to him since.

> He began by doing lots of reading, before deciding that he wanted to use his talents to raise awareness about stomas and the needs of people with them, as well as challenge the deeply engrained stigma attached to having a 'bag'. Ultimately this led to his latest venture: 'There Should Be Unicorns'.

'There Should Be Unicorns' is a family hip-hop musical put together with Middle Child Theatre, a Hull based theatre production company. The story focuses on a young working-class girl called Jasmine, her problems with bullies at school, and her belief in unicorns and superheroes. In the story her father (played by Steve), teaches hip-hop in a traveling bus (based on Beats Bus of course!) and, like his daughter, is struggling. This is because he has a stoma and hasn't been able to talk about what he is going through. Jasmine doesn't understand why life is like it is and dreams there will be a happy ending for both of them. Part way through the play, a turning point is reached where father opens up to daughter. Thanks to some inspired writing by scriptwriter Luke Barnes, Steve in his role as Jasmine's father is able to use hip-hop to convey how stoma surgery saved his life. He also raps about the struggles he faced before surgery. During 2022 the play toured outdoor festivals across England, including events in Hull, Brighton, London and Winchester, sharing stoma awareness and understanding to all those who attended.

Spreading awareness about stomas and the challenges that people with stomas can face (physical and mental) is not as straight-forward as it might at first appear. The trick is to find interesting and engaging ways of getting the message across. Steve has certainly managed to achieve this with his creative approach, using storytelling, acting and hip-hop to tackle the subject in a compelling but accessible manner, that I am sure is particularly captivating for younger people. I can still remember clearly the first time I saw a live performance of a play. I'm sure the same will apply to those who have watched and listened to 'There Should be Unicorns'.

Colostomy Irrigation and You DVD

Order Form Colostomy Irrigation and you (Patients)

Colostomy Irrigation and You is an educational DVD aimed at patients. It has been produced by Colostomy UK to raise awareness about Colostomy Irrigation as a method of bowel management.

Note: Not all colostomates can irrigate. It is therefore essential in the first instance to consult your surgeon/stoma care nurse as they will advise as to your suitability.

To obtain your single copy of Colostomy Irrigation and You at the special price of £1.99 (incl postage and packing) simply fill in your details below and return it with your cheque made payable to Colostomy UK, to:

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

or you can purchase online at: www.ColostomyUK.bigcartel.com

Title: ____________________

Name: ____________________

Address: ____________________

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Tel: ____________________

Email: ____________________

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

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

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

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

Signed: __________ Dated: __________

Please allow 30 days for delivery.
Colostomy UK, 100 Berkshire Place, Winnersh, RG41 5RD | Charity No. 1113471 | VAT No. 917079312

HalfX3 10v00r00 DVD Patients order form | Date of Publication: December 2020 | Copyright ©2018-2023 Colostomy UK | Registered charity no.1113471

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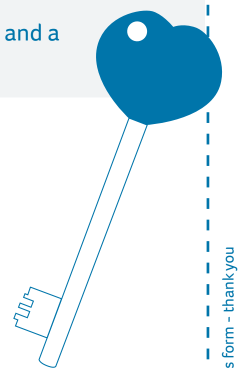
National Key Scheme (NKS) Radar Key and Photo Identity Card

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

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



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

Title: ____________________

Name: ____________________

Tel: ____________________

Email: ____________________

Address: ____________________

____

____

Postcode: ____________________

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

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

Please **tick** as appropriate:

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

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

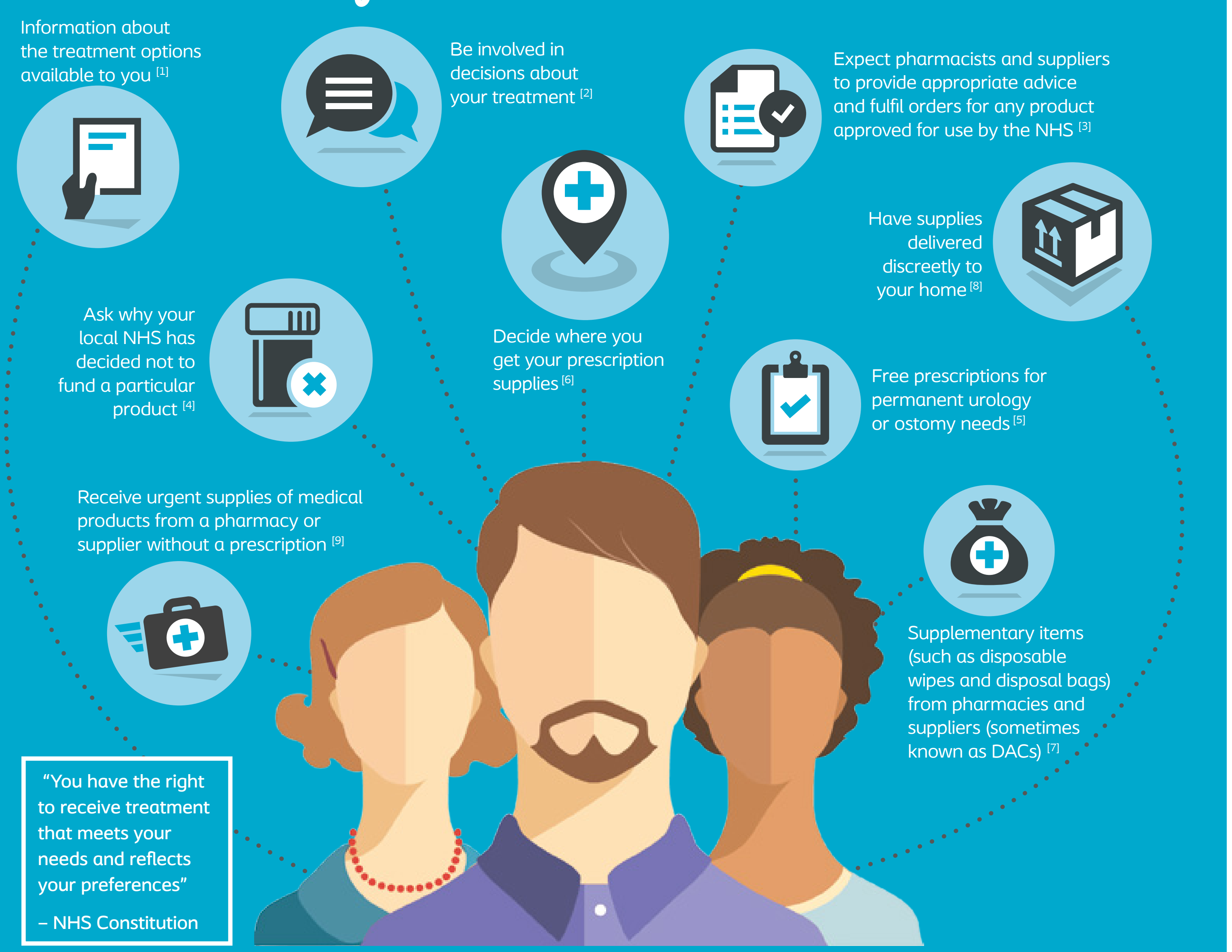
Return all required items to: **Colostomy UK, 100 Berkshire Place, Winnersh, RG41 5RD. Cheques should be made payable to Colostomy UK.** For payment by credit card, send your documents in the post with a contact telephone number, we will then call you to take a card payment when received. (If you have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

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

Your rights England

A short guide to your rights as an NHS patient in England with intimate health needs.

You have the right to...



Information about the treatment options available to you [1]

Be involved in decisions about your treatment [2]

Expect pharmacists and suppliers to provide appropriate advice and fulfil orders for any product approved for use by the NHS [3]

Have supplies delivered discreetly to your home [8]

Ask why your local NHS has decided not to fund a particular product [4]

Decide where you get your prescription supplies [6]

Free prescriptions for permanent urology or ostomy needs [5]

Receive urgent supplies of medical products from a pharmacy or supplier without a prescription [9]

Supplementary items (such as disposable wipes and disposal bags) from pharmacies and suppliers (sometimes known as DACs) [7]

> "You have the right to receive treatment that meets your needs and reflects your preferences"
>
> – NHS Constitution

Questions you could ask your doctor:

- What products are available to help with my condition? What are the advantages of different models of device?
- Could different products help me manage my condition?
- Am I entitled to free NHS prescriptions? Can you give me a medical exemption application form?
- If there is a product you feel would help you manage your condition, ask your doctor or nurse whether they can prescribe it. If they say no, you can ask for an explanation why?

Questions you could ask your pharmacist or medical devices provider:

- Are there any supplementary items that should accompany this product?
- Can you send the order to my home?
- What similar products are available from other manufacturers?
- How do I use and look after these products? Is there anyone I can talk to about it?
- Is there anything you can do to help me manage my condition? Can you prepare me an online personalised care plan?

Further information

"The NHS Constitution establishes the principles and values of the NHS in England. It sets out the rights for patients which the NHS is committed to achieve by ensuring the fair and effective management of resources and care."

[1] **You have the right to be given information about the treatment options available to you,** what they involve and their risks and benefits. *(NHS Constitution)*

[2] **You have the right to be involved in making decisions about your care** and should be offered the opportunity to participate. The Health and Social Care act requires your local NHS to promote patient involvement in decisions about their treatment. *(Handbook to the NHS Constitution)*

[3] **Suppliers should fulfil orders for any appliance approved for use on the NHS.** If they are unable to fulfil an order they must either forward the order on to another supplier (if they have your permission to do so) OR provide you with the details of two other suppliers who can fulfil it.

Suppliers should also be able to **provide appropriate advice** about the products they sell, for example how to use, clean and care for them. They may also be able to offer you **online support to help you manage your condition**, for example by preparing you a personalised web-based care plan. *(The National Health Service (Pharmaceutical and Local Pharmaceutical Services) Regulations 2013)*

[4] Your local NHS has the right to make decisions over which treatments to fund, **you have the right to expect those decisions to be made following a proper consideration of the evidence.** If your local Clinical Commissioning Group decides not to fund a medical device which you and your doctor or healthcare professional feels is right for you, they should explain that decision to you. *(NHS Constitution)*

[5] **You may be entitled to free prescriptions if you regularly use ostomy or urology appliances,** particularly if:

- You have a permanent stoma;
- You need an appliance or continuous surgical dressing because of a permanent fistula (an abnormal passageway between two organs, or an organ and the exterior of the body);
- Are being treated for cancer, the effects of cancer or the effects of cancer treatment; or
- You cannot go out without the help of another person because of a continuous physical disability.

Alternatively, if you are over sixty or are on benefits because of low income you may also be entitled to help with prescription costs.

[6] **You can decide how to get your prescription supplies dispensed.** You can obtain prescription supplies in five different ways:

i. You can let the supply company (sometimes called DACs) handle everything – you place an order with them and they will contact your GP to get the prescription;

ii. You can place an order with a supply company and then send them your prescription yourself;

iii. Your GP can handle everything – you can ask your GP to send the prescription to your supply company of choice. Some GP practices also have a dispensing arm that may be able to provide your appliance;

iv. You can order on the NHS Electronic Prescription Service (EPS) via your GP or nurse. You will need to nominate your supply company and prescriptions will be sent there electronically, reducing delivery time;

v. You can take your prescription to a local pharmacy.

[7] **You have the right to expect pharmacies and suppliers to provide supplementary items** (such as disposable wipes and disposal bags) when fulfilling a prescription for incontinence, stoma, catheter, erectile dysfunction, wound drainage and anal irrigation appliances. *(The National Health Service (Pharmaceutical and Local Pharmaceutical Services) Regulations 2013)*

[8] **You have the right to have supplies delivered discreetly to your home.** The packaging and method of delivering continence, stoma, catheter, erectile dysfunction, wound drainage and anal irrigation appliances must not indicate the nature of what is being delivered. *(The National Health Service (Pharmaceutical and Local Pharmaceutical Services) Regulations 2013*

[9] **You have the right to an urgent supply of appliances from a pharmacy or supplier without a prescription,** if your doctor (or another health professional who can make prescriptions) asks them to do so. This will require your doctor (or the other prescriber) to agree to provide a prescription within 72 hours. *(The National Health Service (Pharmaceutical and Local Pharmaceutical Services) Regulations 2013)*

Colostomy as an Early Active Choice Following Spinal Cord Injury

By Michelle Louise Boucher, PhD, RN
Stoma Care Clinical Nurse Specialist Salisbury NHS Foundation Trust

Colostomy following Spinal Cord Injury (SCI) has traditionally been performed as a last resort many years after injury, when all other forms of bowel management have failed. The last decade, however, has seen increasing numbers of patients ask for it as a first choice. Curiosity about this trend, which goes against accepted professional wisdom, led to research to investigate the experiences of people with SCI who choose to have a colostomy.

Background

SCI is a relatively rare event with approximately 2,500 new injuries per year and at least 50,000 people estimated to be living with spinal injury in the UK (Aspire 2020). Paralysis is an obvious effect, but what may be less well known is the effect SCI has on bowel function. Damage to nerves which control the bowel frequently lead to slower transit of stool through the colon, a lack of awareness of having a full rectum, and reduced or absent ability to expel stool.

To keep bowel function regular and prevent incontinence, professionals have developed guidelines, with the suggestion being that 'conservative' or 'least invasive' methods are used wherever possible (MASCIP 2021). These methods include modifying diet, use of medication, and using manual evacuation or digital stimulation to empty the bowel.

Only if these conservative methods fail, should the 'most invasive' option of colostomy be considered. So why are people with SCI increasingly asking to have a colostomy in the early months following injury whilst they are still in hospital?

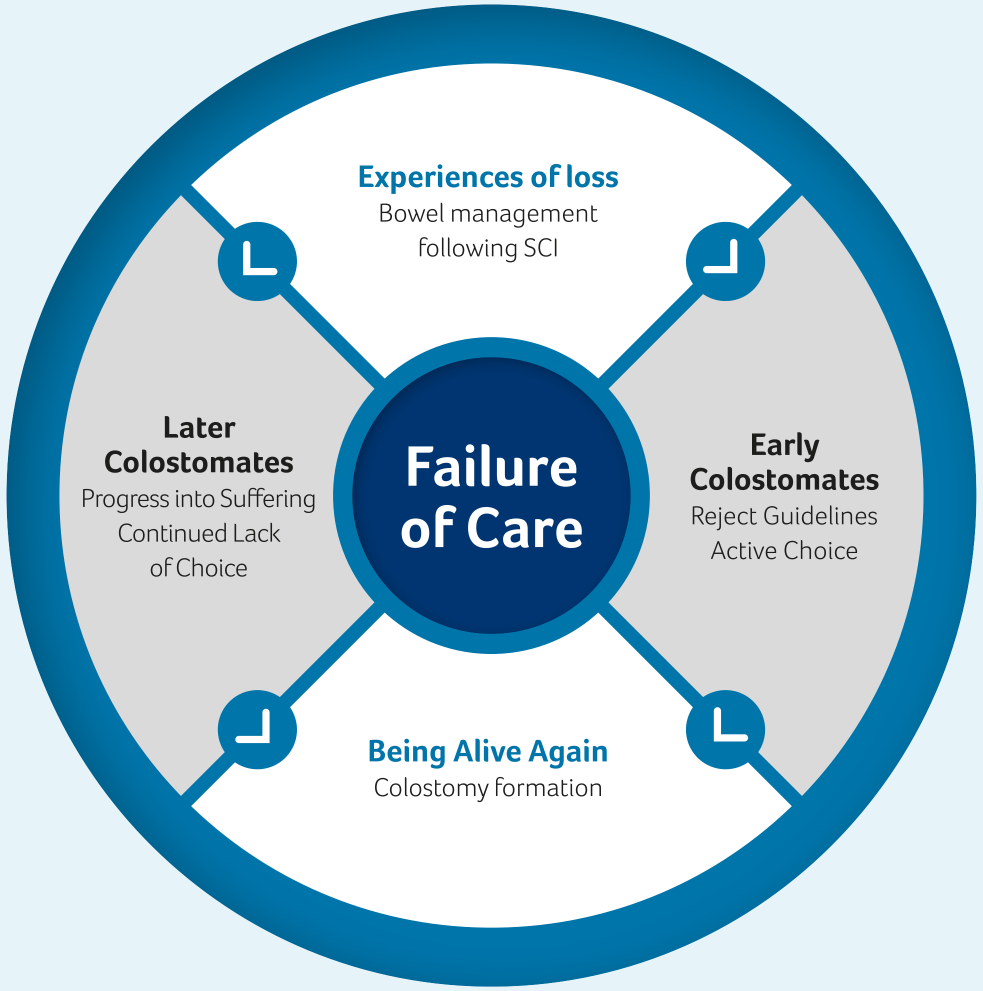
The research

To try and find an answer to this, research was carried out by interviewing people with SCI who have gone on to have a colostomy. Those interviewed were divided into two groups – those who followed professional guidance and had the colostomy 'later' many years after their injury; and those who chose it 'early' whilst still in hospital having rehabilitation.

Findings

The research found four themes from the interviews. These are **Experiences of Loss, Progression into Suffering, Being Alive Again,** and **Failure of Care**.

All those interviewed described **Experiences of Loss** related to their bowel function. These included loss of physical control over their bowels, and also a loss of control about how their bodies were managed. Methods of manually removing stool from the rectum led to a loss of dignity, and many experienced a loss of independence.



The reaction to Experiences of Loss was different for the two groups. The 'later colostomates' followed traditional professional guidelines and Got Used To these Losses. Over the years they then developed complications and difficulties related to their bowel function, and the theme of a **Progression into Suffering** was observed. The process of emptying their bowels became increasingly lengthy and could take several hours, they developed problems including painful haemorrhoids and bleeding, and their bowel function came to dominate their whole lives. When they eventually had the colostomy, it was done as a last resort and was seen as a continued lack of choice about how their bowel function was managed.

In contrast, the **'early colostomates'** reacted to the Losses they experienced by Rejecting Guidelines and professional wisdom. They made an Active Choice to have a colostomy because they saw it as a simpler method of managing their bowels and staying continent, it was easier to be independent with changing the colostomy pouch, and it often meant they wouldn't have to rely on a carer to do this for them once they got home.

After having the colostomy, both groups had experiences which were described as like **Being Alive Again**. The losses of control, dignity, and independence were reversed. The suffering from lives revolving around dealing with their bowel function was gone, and many people found that painful complications resolved. There was a newfound freedom to get on with their lives, socialise and go to work without the fear of bowel accidents, and it was liberating to be able to pursue activities they had previously had to give up due to difficulties with their bowel function. These three themes help to explain why people with SCI are increasingly choosing to have a colostomy and choosing it at an early point after their injury. Colostomy can be a transforming procedure which positively changes lives for the better.

The final theme which the research found was a concerning **Failure of Care**. Many were failed by not being given information about colostomy early enough, and by not being given choice in how their bodies were managed. When patients are asked about their experiences, they find manual interventions to be invasive and colostomy to be non-invasive because all that is required is for a pouch on the outside of their body to be changed once or twice a day. It was seen as a Failure of Care that professionals may assume to know how bowel interventions are experienced and what is best for patients without asking them and involving them more in decision-making.

Some people decided to have the colostomy because it made dealing with their bowel function easier when going into public spaces for instance to work or socialise. This demonstrates people making decisions because of a failure of public facilities to be suitable and accessible to them. Of great concern is the discovery that some people chose to have a colostomy because they were worried about not having access to the care they needed once they went home. This points to systemic failures in the provision of adequate care.

Summary and implications

People with SCI are choosing to have a colostomy because it makes their bowel function easier to manage, increases their independence, and it reverses experiences of loss and suffering. Having a colostomy can lead to a positive experience of Being Alive Again and enables people with SCI to get on with their lives. It is concerning that some people are choosing it because of inadequate public facilities and buildings, and because of a deficit of care provision in the community. More needs to be done to ensure that those living with SCI are aware of the option of having a colostomy and have good quality information so that they can make an informed choice about how their bodies are managed.

Outcomes of the research

Because of this exploration of patient experiences, a regular information session about the option of colostomy has been introduced on this spinal unit, which newly injured inpatients are invited to attend. A new clinic and clinical pathway have been introduced to meet the growing demand. Efforts are being made to ensure that those with SCI can access good quality information about colostomy through publication and presentation of this research. More research is planned to take this work forward.

Aspire, 2020. Spinal cord injury paralyses someone every four hours [online]. Available from: https://www.aspire.org.uk/news/every-four-hours [Accessed 18/05/2021].

MASCIP, 2021. Guidelines for Management of Neurogenic Bowel Dysfunction in Individuals with a Spinal Cord Injury and Other Central Neurological Conditions. Online: Multidisciplinary Association of Spinal Cord Injury Professionals.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WHEN A STOMA BAG FITS RIGHT
IT FITS EVERY SIDE OF LIFE

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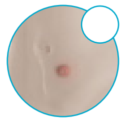
TAKE THE OSTOMY CHECK AND CHECK YOUR FIT

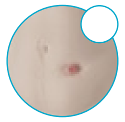
We understand over time that the size of your stoma, your body shape and lifestyle can all change. That's why it is so important you regularly check your stoma care routine and stoma health. As well as ensuring that you are still on the best product solution to fit your body shape, you will feel secure and confident in your everyday life.

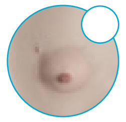
Why not take the Ostomy Check today to help you identify common issues such as sore skin, or problems with adhesion and leakage. We'll then review your answers and a member of our dedicated Coloplast Clinical Services team will contact you.*

Please tick in circles where appropriate

Which best describes the area around your stoma?


○ *Regular*
The stoma opening is above or level with the skin surface


○ *Inwards*
The stoma opening is below skin surface or requires some support due to challenges on dipped areas


○ *Outwards*
The stoma opening is on curved body shape or outward area (e.g. a diagnosed hernia)

Do you have any adhesion issues?

Ensuring your product sticks securely to your body helps you feel secure.
You can tick one or more issues.

- ○ None
- ○ *Insufficient adhesion when applying*
- ○ *Adhesive dissolves during wear*
- ○ *Adhesive edges roll*

Do you have any skin irritation issues?

Your skin around your stoma should look like the rest of your stomach.
If not, you can tick one or more issues.

- ○ None
- ○ *At the outer edge of the baseplate*
- ○ *Under the baseplate*
- ○ *Around the stoma*

Do you have any pouch issues?

It is important that your pouch works for you and that you feel confident wearing it. *You can tick one or more issues.*

- ○ None
- ○ *Leakage*
- ○ *Odour*
- ○ *Ballooning or pancaking*

For two-piece appliance users only

It is important your two-piece works for you. Tick on any coupling issues you might have. *You can tick one or more issues.*

- ○ None
- ○ *Coupling difficult to close or open*
- ○ *Pouch falls off*
- ○ *Leakage at coupling*

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Date of birth ______________________ Email ______________________

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Signature

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Coloplast

dear consultant

Colonoscopy Through the Stoma:

A Patient's Experience

Having a colonoscopy isn't something anyone relishes. But what about having one through your stoma?

From time to time we receive calls from ostomates who are about to have this done. As well as questions such as: what's involved? and will it hurt? callers often express feelings of anxiety around the thought of what might be found. With this in mind, we thought it would be useful to speak to someone who has recently been through the procedure. On the opposite page, Colostomy UK's President Ian Daniels, who is a consultant colorectal and general surgeon at The Royal Devon and Exeter Foundation Trust, explains the procedure from a healthcare professional's perspective.

Our patient is Paul, who is 73 years old and ex-military. Paul lives in Exeter, where he is a full-time carer for his wife. He was diagnosed with stage two rectal cancer in 2019. This came after a 'normal' colonoscopy to investigate the cause of blood in his poo. Paul had stoma surgery in February 2020 and then a colonoscopy through his stoma in November 2021. This was carried out to check that the cancer had not returned. With COVID running rampant around the time of his surgery, Paul elected not to have chemotherapy.

Paul began by saying that the colonoscopy through his stoma was the most nerve-wracking part of his stoma journey so far. But if you are due to have the procedure yourself please don't panic, because as we talked it became clear that it wasn't so much the procedure that Paul was anxious about, but more what it might find. Additionally, having had a normal colonoscopy previously, he knew the effects of Moviprep and managing these with a stoma and stoma bags concerned him.

Paul says he was right about the Moviprep: it was as bad as he was expecting. He ended up needing two two-hour sessions on the toilet, trying to cope with the volume of output and its uncontrollable nature. However, it's worth noting that this experience isn't specific to a colonoscopy through the stoma. Regardless of how a colonoscopy is done, Moviprep has the same effect. The advice is be prepared, have lots of bags on hand and something to do while you are in the bathroom. Paul took his tablet and managed to get some time surfing the internet.

The colonoscopy went smoothly and Paul got his results immediately. These were all positive, although the doctor did pick up he had diverticulitis (but no intervention was required). Paul explained that two nurses were present: one looked after him, while the other assisted the doctor doing the colonoscopy. Paul found this reassuring. It also turned out that the doctor happened to have conducted his first colonoscopy, which helped him to relax even more. Paul had the option to be sedated but decided against this. He explained that the procedure wasn't painful, just a little uncomfortable when (in his words) 'it went round the bend'!

Feeling worried before having a colonoscopy through your stoma is normal. As Paul's case shows, it's not just the physical aspects of the procedure that can cause concerns; there is also an emotional aspect too. But, your healthcare team will be well aware of this and are there to relax and reassure you and also provide for your medical needs, should you prefer to be sedated or need a little pain relief.

Ian Daniels FRCS

Colonoscopy Through the Stoma

For many people with stomas there is an ongoing need to assess their remaining bowel. The procedure is carried out by an endoscopist using a colonoscope.

A colonoscope is a long, thin flexible soft tube about the thickness of your little finger, with a bright light at the end to examine the lining of the colon. It is inserted through the stoma to examine the part of the bowel still in use and through the anus in instances where we need to check redundant bowel.

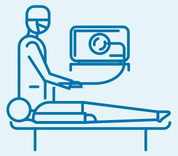
The reasons that people need to have a colonoscope after stoma surgery include:

1. Following emergency surgery, particularly for bowel obstruction secondary to a cancer, it is important to check the bowel upstream to make sure there are no polyps or other problems that would impact on re-joining the bowel at a later date.

2. For those who have had a planned surgery leading to a colostomy, perhaps following rectal cancer, then there is a small increase in the chances of developing a second cancer in the remaining bowel, sometimes called a metachronous cancer. As we understand more about the genetics of bowel cancer, for a small group this can mean annual scopes through their stoma.

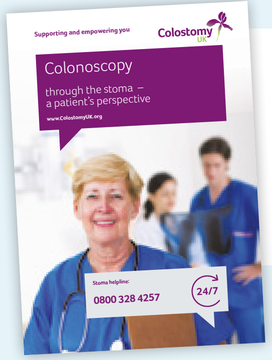
3. Even though we can scope through the stoma, there may be a part of the bowel that is not connected. Not everyone with a colostomy has a Barbie (or Ken) butt. Some people remain with their anus and a section of bowel down below. As many experience, this 'bit below' can produce mucus and it is important that following cancer surgery, this segment is monitored in the short term. For others with conditions such as Crohn's disease there is an increased life-time risk of cancer in the non-connected section and so it needs regular review. When we examine this downstream part of the bowel, the scope is inserted through the anus, without the need for bowel prep.

4. For some who have a defunctioning colostomy, usually prior to any radiotherapy, again the bit below needs to be assessed both in response to treatment but also to view for evidence of stricture.



When we colonoscope through a stoma, there are a few changes. Usually the patient is lying on their back with a couple of pillows and we have removed their stoma appliance (with a spare one ready and to hand… I'll explain later). It is important that their tummy is relaxed, and any hernia is 'flatter'. We also do a digital examination of the stoma. This is a finger examination, just like a rectal examination. It's vital that we do this, as it gives us an understanding of the relationship of the bowel to the abdominal wall. This is so that the scope can be passed inside easily as the abdominal wall, like the bottom, is sensitive.

Colonoscopy uses a column of air to dilate the bowel ahead of the scope so that the route can be seen. As anyone who has had a traditional 'bottom-up' colonoscopy can attest, too much air and it sounds like a marching brass band when it comes out. With a colonoscopy through the stoma it is important to still inflate the bowel in this way, we just have to be careful to avoid blow back from the stoma! Depending on the length of the colon remaining the examination should proceed as normal. The only advice I give to endoscopists in training is to have a stoma appliance to hand ready for when the scope comes out… no one wants to see a geyser in full blow!



Supporting and empowering you

Colostomy UK

Colonoscopy

through the stoma –
a patient's perspective

www.ColostomyUK.org

Stoma helpline:
0800 328 4257
24/7

Call the Stoma Helpline (0800 328 4257) to speak to a volunteer about having a colonoscopy through the stoma. Visit our website to download a copy of our booklet about the procedure.

Jo’s Story

BY LOUISE TURNER

Some opening remarks from the editor

Towards the end of last year Andrew Bird, Colostomy UK’s Clinical Trustee, told me about Louise Turner who is a colleague of his involved in providing stoma care to a gentleman with Down’s Syndrome. Sensing this story would be of interest to readers, I contacted Louise who told me all about Jo and his family. It was only afterwards that I recognised the significance of what I had heard.

Louise tells Joshua’s (Jo) story below. As you will see, it has the feel-good factor. But it is much more than that. Unwittingly, it provides a measure of what can be achieved when providing care in the community to vulnerable people, shedding light on the central role and responsibility that individual healthcare professionals and the wider community have in this. It also highlights the vital part families often play in such circumstances and, in doing so, exposes a weakness in the care system around what happens to vulnerable people when their families pass on or can no longer provide the care they do. As we know, the authorities step in but often they can’t replicate what has gone before – either in terms of who provides the care or the context in which it is given.

Before I hand over to Louise, I want to want to say a little about her. Louise has been working in stoma care for almost two years, having previously been a health assistant in gynaecology and before that a phlebotomist. She was inspired to get into stoma care after her mother-in-law had stoma surgery and she saw first-hand the psychological impact it had on her. Although Louise possessed no detailed stoma knowledge when she applied for her current role, she was told that she had got the job based on her compassion for people, which had come across strongly at interview. Now fully trained, Louise does the occasional clinic for the Nottinghamshire Appliance Management Service (NAMS) / Fittleworth, but most of her time is spent visiting patients in their homes doing annual reviews and reviews. This is how she came to meet Jo.

When we spoke, Louise emphasised how important she felt it was to establish a trusting relationship with her patients and, where applicable, their carers. This is something that can take time and requires particular qualities on the part of the practitioner, beyond just technical competence in their field. The value of trust-based clinical relations is something that has been recognised since antiquity. Hippocrates (yes, I know, it’s the second time I’ve mentioned him in this edition!) saw winning patient trust as giving a helping hand to the ‘healing power of nature’. If ever you wanted proof of the wisdom behind these words, then you need look no further than what follows…

Louise tells Jo's Story:

I would like to share with you the journey of Jo, who is a 41-year-old man who was born with Down's Syndrome and many other medical conditions.

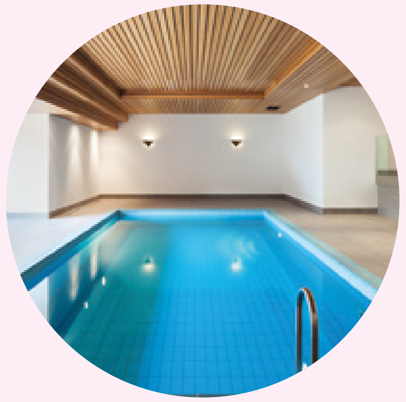
Jo spent the first six weeks of his life with his birth mother but was neglected and left alone. He developed salmonella and was admitted to hospital. Jo's mother decided that she didn't want to take him home and so once recovered he was placed in various foster placements. It wasn't until he was three months old that it was discovered he had Down's Syndrome. When he was 18 months old, Jo was fostered by Bernice and her husband Terry. It was a kind, but also brave thing to do. They had fostered children before and also taken in young pregnant girls until they gave birth, but Jo's needs were different. When he arrived he wasn't walking and as a toddler was doubly incontinent.

I have been seeing Jo for almost a year now and in that time I've built a strong relationship with him and his mother, Bernice. This has helped her to open up about those early days with Jo and some of the struggles that Jo, her, and Terry faced. She recalls just how difficult things were and how they often felt they were having to cope alone. As Jo grew older, he continued to have problems with his bowels and was frequently in pain. By the time he reached his late teens, he was having accidents almost daily. Sometimes these occurred when he was on the bus on his way home from college. Jo was diagnosed with ulcerative colitis when he was in his 20s.

Bernice still gets upset thinking about this period and the years that followed, as attempts were made to manage Jo's condition through diet and intravenous medication. Unfortunately, nothing ever worked for very long and every few months or so he would become very ill. Eventually, with all options exhausted, it was decided that stoma surgery was necessary. In 2015 Jo had an ileostomy formed. Bernice explained to him what was going to happen, and Jo was happy to go ahead, knowing that the surgery should take away the pain that had been an ever-present part of his life for so many years.

After the surgery Bernice really struggled to deal with Jo's stoma, both from a psychological and practical point of view. She says that the consultants were all excellent, but what she didn't get (and didn't really know she needed until years afterwards) was more support prior to and after Jo's surgery to prepare her as his main carer. It was as she and Terry tried to cope with the fresh demands placed on them that their neighbour Tony became involved. He was very supportive and helped them as a family accept that a stoma was going to be a part of Jo for the foreseeable future. Initially, it was hoped that Jo's stoma would be temporary. But a year or so after his surgery, it was discovered there was a possibility that Jo had cancerous cells and so it was decided not to proceed with a reversal.

Although Jo is not capable of changing his bag on his own, he has nonetheless adapted well to having a stoma. He is aware if he has a leak and tells Bernice. If this happens during the night, then he tells her she is the best woman in the world. In many respects Jo's stoma has freed him to enjoy life more. He attends the local fire headquarters once a week, which he thoroughly enjoys. He is also the member of a choir, which he isn't quite so keen on, as he says it is too loud. He also works with neighbour Tony at his aquarium 1-2 days a week, where he sweeps up, feeds the fish and, during the pandemic, made sure he guided the public in the right direction and instructed anyone not wearing a mask to put one on!



I've learned from Bernice that there are some activities that Jo can't do or is reluctant to do. One of these has been swimming, as he is embarrassed about his pouch. But recently, with the support of another ostomate from the support group he attends, Jo found the courage to swim again. Another has been camping. Here the reason is practical, as for Jo to go away, he needs to have someone there who has been trained to do bag changes. Last year, Jo finally started going camping with Tony and David who were able to care for him, as well as keep an eye on what he ate.

Jo also has a sister called Abigail (Abi) who has Down's Syndrome too. She was adopted by Bernice and Terry when she was a baby. Until recently a big concern they held as parents was what would happen to Jo and Abi when they became too old to care for them. As I mentioned at the start, Jo is now 41-years old. For Bernice, the idea that they might be separated just didn't bear thinking about. This worry has resolved itself in a most remarkable way. During lockdown, neighbours Tony and his husband David (who have been neighbours for over 12 years) ended up moving in with Bernice, Terry, Jo, and Abi. This was because work on their own property could not be completed while the pandemic raged. They ended up staying for a year! And, during this time Jo and Abi formed a close bond with them. Hence, when the time comes, Jo and Abi are going to live with Tony and David. Bernice struggles to express how this makes her feel, knowing that Jo and Abi will stay together and live in a loving and caring environment. Jo already goes over to Tony and David for sleepovers, which he enjoys, as apparently they let him watch TV for longer!

I feel privileged to know Jo and his family. I look forward to visits and am pleased that both Jo and Bernice have accepted me as part of the team. The trust that has developed between us all has got stronger over time. Jo is a very compliant patient. When I arrive, he gives me a big hug and kiss on the hand. He then lies still while I examine him. During a review Bernice uses sign language to communicate with Jo, and so I am in the process of learning this so I can follow what they are saying. When a review is finished, Jo will put on some Jason Donovan so we can have a quick dance. As you can see from the photos, he is also a huge Lord of the Rings fan. On my last visit, I was treated to a sword show he had put together that was inspired by the film. Jo had a sad start to life, but I hope you have enjoyed reading how his life is now a happy one!

Colostomy UK

Recycle and Raise Funds

We've teamed up with 'iCollectClothes' to offer a hassle-free way of donating items you no longer want.

They will collect clothing, shoes, linen, bedding, towels, curtains, accessories (bags, belts, hats, scarves), books, DVDs, CDs, soft toys, electronics and small domestic appliances and convert them into a donation for Colostomy UK.

Donations allow us to continue focusing on the things that matter to you - supporting and empowering ostomates.

If you live in London and the South, The Midlands, North West, or North East you can book a collection online. For all other areas give them a call and they will be able to advise when they will be collecting near you.

Book your collection by calling **0344 879 4417** or book a collection online at **icollectclothes.co.uk/donate/colostomy-uk**

iCollectClothes

Colostomy UK

As if by **magic**....
Make your donations worth
25% more
at no extra cost to you!

If you're a UK tax payer, tick the Gift Aid box on the donation form (see page 39) so that we can claim an extra 25% from HMRC at no cost to you. Gift aiding your donation provides us with more funds to focus on the things that matter to you, such as providing support through our stoma helpline, campaigning for stoma-friendly toilets, producing this magazine, or getting more ostomates up and active. For more information email GetInvolved@ColostomyUK.org

☑ giftaid

Colostomy UK

volunteers

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

The East Kent Pathway for Excellent Stoma Care

BY DAVID CHRISTIAN

As a Colostomy UK volunteer on the Stoma Helpline and also a member of the private Facebook group I've come to realise that there is a huge variation between the stoma care ostomates in East Kent receive (where I am based) and other parts of the country. Some services available in one area, such as out-of-hours support or stoma nurses attending support group meetings, are not provided in others. If you don't feel that the support and care you receive is up to scratch then it may be worth considering how to go about improving the situation. What follows is a brief summary of how patients in East Kent have been central in driving forward local improvements.

Until 2014 the stoma patient care system in our region was disjointed, with no clear connected patient pathway of care from diagnosis to pre- and post-operative care and ongoing support afterwards. Acknowledging this to be the case, the Care Management Team resolved to revamp local provision. The aim was to better serve patients and keep costs under control, through improvements to the service and greater efficiency.

Moving forward with their plans, the Care Management Team were keen for patient involvement. There was thus the opportunity for ostomates to be integral to the process and to have their needs and wishes considered. To achieve this each of the local stoma patient groups were approached by a member of the stoma nursing team for their thoughts on what the stoma care package should include, taking account of what was good, bad and indifferent about the current service and how that service going forward should be managed and updated. This of course required people to step forward, and thankfully they did!

Following several meetings and numerous cups of coffee and packets of biscuits the process resulted in the eventual creation of 'The Ostomist Agenda' which was a list of basic requirements:

EAST KENT STOMA GROUPS

The Ostomist Agenda

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

- To be introduced to a specialist nurse who will be looking after me after I have got my stoma and who will talk to my GP about me and my needs with a stoma.
- To have all of the implications of having a stoma explained to me including how I get my stoma supplies and the kinds of problems that can arise with a stoma, including the risk of hernia and the use of support garments.
- To have access to services to support my psychological well-being, especially in the period when I am adjusting to the idea of life with a stoma.
- To have a chance to talk to someone like me who has a stoma.
- To be introduced to my nearest Stoma Friends Group and helpful social media groups.

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

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

As someone with a stoma I expect:

- To be able to contact someone who can advise and help me even at weekends and in the evening.
- Not to have to travel to the hospital every time I have a problem with my stoma.
- My GP and my practice nurse to be able to offer me some basic advice and help when I have a problem with my stoma.
- To be seen by a specialist nurse at least once a year to review my stoma and the appliances and accessories that I am using.
- To have access to services to support my psychological well-being with any problems relating to my life with a stoma.
- To be offered the most up-to-date and effective appliances and accessories which best suit me and my stoma.
- To be able to get into hospital quickly when I really need to.
- To be told when and where my nearest Stoma Friends Group meets and about any helpful social media groups that I can join.
- To have my Stoma Friends Group supported.
- Help for my Stoma Friends Group in promoting Stoma Health and Well Being Days which benefit the whole stoma community in East Kent.

It took time and dedication to draw up the agenda, and make sure nothing important was missed. The leading force behind it was a smaller team of representatives drawn from stoma support groups in East Kent. This highlights another area that is not replicated across the country: where support group representatives meet on a regional basis to form a more powerful patient voice. In East Kent, these regional meetings include representatives from the supply Industry, the stoma nursing team and other interested parties.

Having established what was required by patients, the nursing team, and commissioning body, the next step was to specify what would be required in addition to the current provision to be able to deliver the service. This included:

- Health care assistants to release specialist nurses to concentrate on complex cases.
- Administrative support again freeing up nurses' time.
- Telephony service to support post operatively.
- Annual patient reviews.
- IT system able to monitor what was going on.

It was clear all these improvements were not achievable in one move, so once again patients were involved in prioritising the list. This led to the eventual creation of a tender document which specified all that the supply partners would need to provide in order to meet the requirements. The tender process was initiated and interested supply companies were approached to put together their proposals and bids. Patient representatives were engaged in the evaluation of the bids to ensure that the Ostomist Agenda objectives would be satisfied. Once agreed upon, the five-year contracts were awarded to the selected supply partners.

During the intervening years the Ostomist Agenda has become the framework against which patient services are developed and delivered. This approach has resulted in a strong partnership between patients, nursing staff and the supply companies, all of whom are fully onboard with the process. Being an organic process there is still room to develop services as we move forward.

As patients we benefit from a much more structured and clearer pathway of care. The quality of care has markedly improved too. This has been confirmed by canvassing the opinions of members of local support groups and our social media group. The testimony of those with experience of stoma care in other regions has been especially telling. It is clear that we are very well served. Here are just a few examples of services that ostomates in East Kent benefit from, which do not appear universally available across country:

- Pre op meeting with Stoma Nurse to discuss "positioning" of the stoma and supply of "dummy" stoma and bag and gel.
- Information on local support groups, and National Support Charities.
- Home visit follow up (post operative), followed by two weeks of daily telephone support.
- Review appointments made at local GP Surgery rather than in the Hospital.

We are not complacent, realising that there is always room for improvement. In the future, we want to develop a 'Stoma Buddies' network so that a new patient facing stoma surgery can, if required, be paired up with a local buddy to mentor and support them through their journey. We also acknowledge that GP services, especially from a prescription supply point of view, need to be more engaged with the Agenda. Efforts continue to be made to improve this situation.

At the sharp end as a patient, having a motivated, engaged and dedicated stoma nursing team and supply network results in one of the best stoma patient experiences I have come across. If more regions had this sort of structure in place, I am sure we would see an improvement in the quality of life for many ostomates around the country. But, of course, improvements rarely happen on their own. Instead, it needs people to step up and drive this sort of initiative forward. If you would like to learn more about how the East Kent system evolved and now works, then please contact Colostomy UK.

Fundraising

Our **NEW #StomaAware t-shirts** are available to buy via our shop!

Colostomy UK

Show the world that you're Stoma Aware and encourage others to be too with our brand new t-shirt.

These stylish tops are £17.99, and available in sizes **Small** to **XXL**.

The t-shirts are 100% cotton, and feature our Stoma Aware logo on the front and ColostomyUK.org on the back.

Get yours via our website shop:
ColostomyUK.bigcartel.com

Find us on
Facebook

Colostomy UK

campaigns

Giovanni Cinque
Marketing & Campaigns Manager
GetInvolved@ColostomyUK.org

#StomaAware

Stoma-Friendly Toilets

It doesn't matter whether it's a trip to the shops, off to see a show, or visiting a tourist attraction, knowing that there are easily accessible public toilets is an important consideration for many people with stomas. It's like a comfort blanket, something that takes the stress out of the day.

As a consequence of our campaigning, Butlins, Stoke City, Lords, West Bromwich Albion, Tranmere Rovers, Milton Keynes Dons, Sainsbury's, The Theatre Royal and Royal Concert Hall Nottingham, West Yorkshire Police, The Grosvenor Chester, and the Walker Art Gallery Liverpool have all made their accessible toilets stoma friendly.

What makes a toilet stoma friendly?

When we work with organisations, we provide them with the following guidelines:

Essential

- Hook on door – To hang clothing, handbags and luggage while changing stoma bags. This provides more space in the cubicle.
- Shelf space – To enable ostomates to spread out their items easily and avoid having to use unsanitary surfaces.
- Mirror (ideally, full length)– To enable users to see their stoma while changing their appliances.
- Disposal bin in every cubicle – To avoid embarrassment for men and women having to dispose of their stoma bag in public view.

Recommended

- Accessible #stomafriendly toilet signage – To highlight that not all conditions are visible. We offer our stoma friendly toilet stickers free of charge.
- Accessories – Ensure toilet roll, paper towels, handwash and other items are well-stocked.

For further information on the guidelines please visit our website.

What are we doing to increase the number of stoma friendly toilets in the UK, and how can you help us?

We are working all the time to encourage businesses of all sizes to adopt our guidelines. We have also joined forces with Level Playing Field who campaign to make sports stadia more accessible for disabled supporters and AccessAble who provide listings of accessible facilities.

In 2023 we plan to engage more with policy makers to help push toilets higher up the agenda for both local and central government.

We want our campaign to be a catalyst for change but we need your help.

We've created a series of tools that you can use to present to councils, businesses and organisations in your area, to encourage them to make their facilities stoma friendly. These include a letter you can print off and send, our stoma friendly toilet guidelines and a Stoma Aware poster. They can be downloaded from our website **www.ColostomyUK.org/campaigns** or if you'd like us to send you hard copies email **GetInvolved@ColostomyUK.org**

> If every reader convinced just one business to become Stoma Aware they'd be over 60,000 places more welcoming to people with stomas. Now that would be real change!

To whom it may concern

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

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

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

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

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

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

#StomaAware

More information

ColostomyUK.org/StomaAware

What is a Stoma?

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

*A stoma can be temporary or permanent

There are three main types of stoma:

Colostomy – Diverts faeces from the colon

Ileostomy – Diverts faeces from the small intestine

Urostomy – Diverts urine away from the bladder

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

160,000 People in the UK have a stoma

Who has a Stoma?

Anyone can have a stoma.

Why do I need to be Stoma Aware?

Not all disabilities are visible

#stomafriendly

Empower people to access the information and Support they need.

To stop Prejudice and discrimination.

Why do people need a stoma?

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

The stoma friendly toilet

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

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

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

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

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

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

Not all disabilities are visible

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

- » Stoma Friendly Toilets letter
- » Stoma Aware Speech poster
- » Stoma Friendly Toilets guidelines

Please support Colostomy UK

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

Colostomy UK

My Details

(Please complete in **BLOCK CAPITALS**)

Title*: First name*: Last name*:

Address*:

Postcode*: Phone Number:

Email*: Date of birth:

Gender: ☐ Male ☐ Female ☐ Other, please specify:

If you are new to **Colostomy UK**, how did you hear about us?

Are you: ☐ An ostomate ☐ A carer ☐ A healthcare professional ☐ Family or friend

☐ Other, please specify: Stoma type: ☐ Colostomy ☐ Ileostomy ☐ Urostomy

Date of surgery: Reason for surgery:

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

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

☐ Monthly **Colostomy UK** support e–newsletters

☐ Post from carefully selected third parties (eg about open days or offers)

☐ Emails from carefully selected third parties (eg about open days or offers)

Any other details you would like to share with us

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

My one-off donation

☐ £25 ☐ £30 ☐ £50

☐ Other amount (please state) £

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

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

Card number ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐ *(Maestro only)*

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

Signed Date D D M M Y Y

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giftaid it **Thank you for your gift**

Thanks to the Gift Aid scheme – we can reclaim money on your donation from the government. For every pound you give us, we can claim an extra 25p. For example, a donation of £20 becomes £25 with Gift Aid, at no extra cost to you.

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

Signed: Date: / / 2023

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

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

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Providing NHS services

TEAM Colostomy UK

campaigns

Giovanni Cinque
Marketing & Campaigns Manager
GetInvolved@ColostomyUK.org

As you read this, Team Colostomy UK will have played their first Rugby League game of 2023 against the Royal Navy. Included in the line-up was Matt Turner, a Team Colostomy UK original. He's also one of our players who doesn't have a stoma. Matt had this to say:

In many ways, Team Colostomy UK is like any other Rugby League team. We fulfil fixtures. We have a group chat that goes off 24/7 with views on games, memes and general banter. We all make it our mission to give our team manager a hard time, and we all love Rugby League. The only difference (and it's a big one) is that most of the guys and girls in the team have a stoma.

I got involved through Giovanni. We worked together we before he Joined Colostomy UK. I was a community Rugby League coach in Croydon and he was a community development manager for the Rugby Football League in south London. When he contacted me and asked if I would play, I was more than happy to get involved, but had no idea what a stoma was! Of course, I've found out since, which has only added to the respect I feel for the ostomates in the team. Rugby League is not just a contact sport but is arguably the most physical collision sport there is. Studies have shown that in a tackle you can experience up to 21-22 G-force, which is crazy when you think that a 40mph car crash results in a G-force of about 35. I can't imagine what that might be like if you have a stoma. Just the courage to play amazes me, yet these warriors are taking these collisions and smiling afterwards. It's phenomenal.

Being involved from the start means I have many great memories, from playing alongside Rugby League legend Paul Anderson, to having Josh Charnley and Owen Farnworth as our water boys. My favourites however, are those moments when a new player makes their debut. There is always a level of anticipation and nervousness while they are kitting up. I can only guess what is going through their mind. This could be the first time they have played since their surgery. What makes these memories so special for me is their face after that first tackle. It goes from being nervous to having the biggest smile. In that tackle, in that second, we have changed not only their perception of what can be achieved when you have a stoma, but also that of their friends and families. Some of these players have gone on to play for their local clubs, something they never thought they would do again, and one player (Ryan Owens) has even gone on to score the match winning try in the PDRL final for Leeds Rhinos!

The other thing I like about playing for the team is the opportunity it provides to tell people what stomas are. Over time, I believe this will help get rid of the stigma associated with stomas. It's a cause that I feel very passionate about. I have even introduced a couple of players to the team (neither have stomas), and they too are as keen as I am about spreading the message.

Matt Turner

You can still play for us even if contact Rugby isn't for you. Our players in gold shorts play Touch Rugby rules instead. So everyone can participate regardless of age, sex or ability!

If you would like to get involved, get in touch via **GetInvolved@ColostomyUK.org**

Your Letters and Emails

Editor's note:

Thank you to everyone who has been in touch since the last edition. The post bag was a little lighter than usual, although I think this had a lot to do with Christmas and, of course, the postal strikes. Travel remained a popular theme, so I have included a couple of letters/emails below.

Dear Editor,

I had bowel cancer 12 years ago which led to me having a stoma.

Since then, I have had one particular issue that has made my life fairly intolerable. At times (it could be once or twice a week or month) I suddenly get considerable pain in my left side lower back region. This is followed usually within 20 minutes or so by my bowel completely emptying of all contents which invariably is too much for the general size of bag to handle. I find the larger bags uncomfortable to wear.

This has led to major changes in my lifestyle, I can no longer fly or go on long car journeys in case this occurs, which makes holidays out of the question. In addition, I have two grandsons who are sports enthusiasts and who I like to take to events around the country. I find the only way I can reduce the possibility of my bowel emptying suddenly is to not eat at all for three days before we are due to go to the event. Although this can alleviate the problem to an extent, it is not good for my general health.

I wonder whether any other colostomate suffers the same problem? I have discussed my condition with my consultant and stoma nurses in the past but no one can provide an answer. I am 80 now and as my grandchildren are growing up (15 & 17) I am finding it more difficult to enjoy time with them.

Mr B N

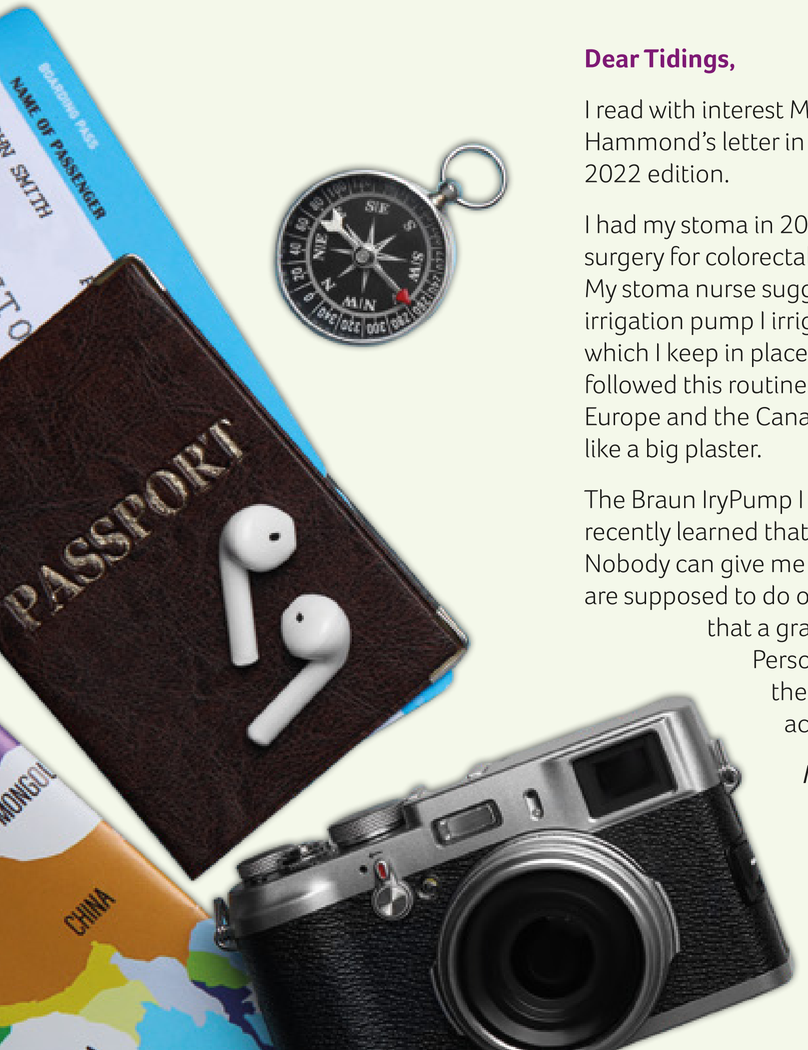
Dear Tidings,

I read with interest Moira Hammond's letter in the Winter 2022 edition.

I had my stoma in 2004 following surgery for colorectal cancer. My stoma nurse suggested irrigation. Using a Braun irrigation pump I irrigate every morning and then insert an Assura Coloplast plug, which I keep in place until the next morning when I repeat the procedure. I have followed this routine faithfully with just a few hiccups. This has included flights to Europe and the Canaries. Like Moira says it is fabulous for swimming and looks like a big plaster.

The Braun IryPump I use is a brilliant machine, perfect for traveling, but I have recently learned that Braun has stopped manufacturing irrigation machines. Nobody can give me information about what those ostomates who use one are supposed to do once their machine needs replacing. It has been suggested that a gravity machine is the only way to irrigate in the future. Personally, I didn't have much joy using the gravity machine in the past. Does anyone know why we will no longer be able to access an automatic machine?

Many thanks, Nigel Baillie



Dear Editor,

I 'joined' the stoma / hernia club in June 2021. I believe much involved in getting used to it is gaining confidence.

This I severely lacked concerning travel. Before going to Portugal I thought it best to book through a travel agent (in our case Barrhead) for back up. They were able, with EasyJet from Bristol to Faro, to obtain for me/get for me:

- Priority seating (ask for near the loos)
- Priority boarding
- Use of the special needs queue
- Informing the staff, who were totally supportive

When I got to security, they were so kind re extra supplies aerosols, procedures etc. that I was almost in tears of gratitude. The same applied to Faro.

In addition, Barrhead Travel joined us to the Lanyard Scheme, which operates at most large UK Airports – thus alerting staff to your needs.

Finally, we travel extensively in the UK. I advise hotels of my condition and requirements – extra towels, sanitary bin – I have a few major accidents, but in each case the hotels have all been understanding.

Our condition takes a lot of getting used to, but in the main people and organisations are sympathetic and kind.

Robert from Devon

From the editor - I was contacted by a reader in the summer who had found a useful page on Manchester Airport's website all about the Sunflower Lanyard Scheme: ***www.manchesterairport.co.uk/help/special-assistance/invisible-disabilities****.*

Given that this airport has received poor press in the recent past, I asked her to report back on how the scheme worked at Manchester for a trip she was making in October.

This is what she had to say:

'Your secret shopper reporting in… The Sunflower Lanyard was a great help, we were identified and picked up by staff from check in. Going through the scanner at the new Terminal Two was fine and it did not bleep because of my stoma. We also went through the luggage search without hitch, apart from a few questions about the complimentary water spray in my equipment bag. So, my experience was a positive one.'

Thanks to Meg S for doing this.

We look forward to hearing from you, our readers:

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

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

Please make sure you **include your full name** and **contact details**, and confirm that Colostomy UK has permission to publish your letter. Also **indicate whether you would like us to use** your **full name** or **just your first name**. If you do not give us permission to use your name we will publish only your initials.

News from Support Groups across the UK

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

If you are thinking of starting a support group in your local area or are perhaps about to take over the running of an existing one, then please don't hesitate to get in touch with us for advice.

Tel: **0118 939 1537** or email: **hello@ColostomyUK.org.**

Bowel Buddies Preston Colorectal Cancer Support Group

We are a recently formed group, run by patients for patients to provide a safe and welcoming environment where you can meet and talk with others who have had similar experiences.

'Don't Bowel Down to Cancer!'

We meet on the **4th Wednesday of the month** between **6-7:30pm** at **CancerHelp's Vine House, 20-22 Cromwell Road, Preston, PR2 6YB**.

For more information contact either Vine House **01772 793344** or Calum **07463 880652**.

Bristol Ostomates Self Support Group (BOSS)

Meets quarterly in central Bristol at St James Priory (behind Bristol Bus Station) but members also come from Bath, Weston-Super-Mare and Somerset.

BOSS also offers listening support especially for people who are facing operations and require some practical advice on living with a stoma.

Helen our Stoma Nurse normally attends meetings. There is also a raffle and refreshments and the opportunity to chat with fellow members. All meetings start at 2pm and normally finish before 4pm. (Open Day at The Future Inn 10am-1.30pm). There is a small admission fee of £1 per person and our 2023 membership remains unchanged at £6 single and £10 couple. Potential members are always welcome to give us a try.

Summer Meeting Saturday 3 June, Speaker Aileen Fraser, IBD Advanced Clinical Practitioner, Lead Inflammatory Bowel Disease Nurse at the BRI. Trade: Melanie Timothy, AMI/Suportx.

Full details of BOSS are available at **www.ostomy.org.uk** or via email on **info@ostomy.org.uk**. We welcome enquiries!

Wessex Stoma Support Group

Wessex Stoma Support Group had a busy 2022.

We enjoyed hearing from a variety of speakers at our meetings in the Bob Blandford Hall in Wilton, including a talk by Patrick Cashman from the RSPB. We re-started our tea and chat afternoons in the Tesco Community Room accompanied by activities such as Creative Arts, watercolour painting and a game of Boccia. In addition, the carers' group (now called the Primrose Group) which is for carers and those who have lost partners, had regular cream teas at Britford Farm Shop. We held our annual BBQ, and a seaside trip with a boat ride to the Isle of Wight, then finished the year with a Christmas lunch at the White Hart Hotel, a trip to the Pantomime and a Christmas Party at our December meeting. We also continued our local Stoma Aware campaign.

For more information and details of 2023's meetings visit: **www.wessex-stoma.co.uk**, email **info@wessex-stoma.co.uk**, or contact Karen Berryman on **01980 590 599**.

Outlook, The North Staffs Ostomy Support Group

Meet around every two months at **Bradwell Lodge Community Centre, Bradwell Lane, Newcastle Under Lyme, Staffs, ST5 8PS**. Meeting are also held in Stafford.

For further information please contact Moira Hammond on **07788 402195** or email **cm.hammond@ntlworld.com**.

Channel Islands

Guernsey

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

Jersey

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

England

Berkshire

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

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

Bristol

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

Buckinghamshire

High Wycombe Stoma Support Group
T: 0800 318965

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

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

Cambridgeshire

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

Cheshire

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

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

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

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

Cleveland

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

Co. Durham

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

Darlington Support Group
Margaret Clothier
T: 0191 333 2184

Durham Stoma Support Group
Lynn Ridley
T: 0191 333 2184

Cornwall

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

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

Cumbria

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

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

Derbyshire

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

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

Devon

Devon IA
E: devon@iasupport.org

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

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

Dorset

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

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

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

Essex

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

Mid Essex Stoma Support Group
Paul Fox T: 01245 441 894

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: 01268 451 937
E: stepsessex@gmail.com

Hampshire

Replummed Stoma Support Group
W: www.replummed.me

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

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

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

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

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

Herefordshire

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

Hertfordshire

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

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

Isle of Wight

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

Kent

Ashford Stoma Support Group
Malcolm Jones T: 07709 534463

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

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

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

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

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

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

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

Thanet Stoma Buddies Support Group
Kathy T: 01843 291 825

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

Lancashire

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

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

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

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

Leicestershire

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

Lincolnshire

Grantham Support Group
Bobbie/Rachel T: 01476 464 822

London

Bowel & Other Cancer Support Newham
T: 020 8553 5366

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

Newham Stoma Support Group
Lauren King T: 020 7055 5576

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

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

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

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

Merseyside

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

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

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

Middlesex

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

Norfolk

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

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

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

Northamptonshire

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

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull T: 07714 479 320

Hexham Ostomy Group
Marie Douglas T:07941 433 600

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

Nottinghamshire

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

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

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

Shropshire

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

Somerset

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

Staffordshire

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

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

Suffolk

East Suffolk Ostomy Group
Ian Denison T: 01473 684865

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
T: 01483 571122 ext 2558

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

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

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

Worcestershire

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

Yorkshire

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

Airedale Stoma Support
Sue Hall T: 01535 646 373

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

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

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

Bradford Stoma Support Group
Lisa Hall T: 07552 276 747

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

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

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

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

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

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

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

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

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

County Armagh

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

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

County Down

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

Ulster Hospital
Hazel/Martina T: 028 9055 0498

Londonderry

Causeway Support Group
Mary Kane T: 028 7034 6264

Republic of Ireland

County Mayo

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

Dublin

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

Scotland

Ayrshire

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

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

Fife

Fife Ostomy Support Group
Ishbel Barr T: 01592 772 200

Greater Glasgow

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

Moray

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

Scottish Borders

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

South Lanarkshire

South Lanarkshire Stoma Support group
Val McNeill T: 07903519924
E: valmcneill20@hotmail.com

West Lothian

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

Wales

Aberystwyth

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

Bridgend

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

Carmarthenshire

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

Conwy

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

Gwent

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

Mid Glamorgan

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

Pembrokeshire

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

Powys

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

Rhondda Cynon Taf

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

Swansea

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