Autumn 2021 | Issue 63

Colostomy UK

AWARD-WINNING

Tidings

Supporting & empowering ostomates

The Colorectal Ward at Peterborough City Hospital are Stepping up For Stomas this September

ALFRED LEVY
Steps down
as a trustee

ERIC DOUGLIN
Emergency
stoma surgery

Real stories
Real people

Colostomy UK

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Cover photo: Peterborough City Hospital: Colorectal Ward

Dear readers

Although you won't be reading this until September, it's actually mid-July as I sit down to write.

The news is dominated by the long-anticipated lifting of restrictions later this month. Like everyone, the Colostomy UK team is keen to get back to 'normal', but people's views differ on issues such as whether to still wear a mask while shopping etc. Indeed, with all the debate that is going on in the office, it sometimes feels like I'm trapped in a 'Two Ronnie's' sketch set down the pub! The other key news (at least for me as a follower and sometimes player of football) is England's performance in the European Championships. It was shame we didn't win, especially as Giovanni (who looks after our fundraising) is an Italian. The after taste of loss is, however, sweetened slightly by having beaten Germany. However, I've been told not to go on about football, as apparently not everyone likes it?!… so instead I will start by saying a big Thank You to everyone that completed our survey about the service received from the companies that manufacture and deliver stoma products. If you'd like to have your say, see page 8 for details. I also want to mention our AGM. This will be held virtually on 20 September. If you would like to attend and hear updates on our services and campaigns, then keep an eye on our website and social media for details of how to join or email: marketing@ColostomyUK.org.

We have four Real Lives stories in this edition. James Cunliffe who is a PE teacher, talks about what helped his recovery from stoma surgery. Eric Douglin's story throws light on the issues faced by some patient groups accessing support both pre-and post-operatively. Our other two stories, from Rachel Reed and Sophie Brown, look at two young women who have stomas as a result of cancer. Although the symptoms of bowel cancer are touched on in their stories, I recommend readers visit the Bowel Cancer UK website (www.bowelcanceruk.org.uk), as it is so important to act quickly (and encourage others to do so). You can also read about their 'Never Too Young' campaign, which is relevant to both stories.

Emma Vernon who is a SecuriCare stoma care nurse has written our Dear Nurse feature, which looks at parastomal hernias. Staying with healthcare professionals, Hilary Kennard from Bristol Royal Hospital for Children, reports on some research being done into school-age children with stomas. The study is still ongoing but is already revealing some important differences between the perceptions of surgeons and the 'lived' reality of having a stoma as a child. Finally, you will find all the usual news from Colostomy UK. In particular, I would like to draw your attention to our 'Step Up for Stomas' challenge. Taking part is very easy and doesn't require you to do anything too strenuous (unless you want to!). We are hoping this challenge will help to get people active while at the same time raising some funds for Colostomy UK and spreading awareness about what it's like to have a stoma.

Best wishes,

Richard

Richard Biddle
Editor, Writer & Researcher


Ultra Frame
can you see it?

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.
info@ColostomyUK.org

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

Editorial Enquiries

Letters, articles or other submissions
Colostomy UK, Enterprise House,
95 London Street Reading,
Berkshire, RG1 4QA
info@ColostomyUK.org

Advertising enquiries

For a media pack and advertising rates:
0118 939 1537
Marketing@ColostomyUK.org

Social media:

Find us on
Facebook

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

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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 25 for our donation form.

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

Colostomy UK

news

Libby Herbert
General Manager
Libby.Herbert@ColostomyUK.org

Care and Support Alliance

#KeepYourPromiseBoris

On 24 July 2019 the Prime Minister promised to 'fix the crisis in social care once and for all.' Since then, over two million requests for care have been refused.

The commitment to bring forward proposals on social care in 2021 were restated in this year's Queen's Speech but we have yet to see decisive action.

Colostomy UK has been part of the Care and Support Alliance for over five years. On 18 June 2021, together with 50 other charities in the alliance, we decided to act and sent a letter to the Prime Minister urging him to keep his promise.

In the letter, we said: 'Every day we see both the enormous benefits of good social care when it is available and delivered well, and the awful struggles and misery of those who either can't get care at all, or for whom it is inadequate in terms of quality or quantity. We also see the toll on unpaid carers of supporting someone they love without enough back-up from understaffed and underfunded services.'

We have seen reports that the government are considering making funding reform (probably a 'cap' on catastrophic costs) the centrepiece of their care reforms. In the Alliance's view this would not be enough on its own to meet the promise to 'fix the crisis in social care'. In the letter we called on government to do two things: first, invest significantly in councils' social care budgets; and second, ensure care staff get a fair rate of pay and the professional respect they deserve for the important work they do.

You can find out about the Care and Support Alliance and the **#KeepYourPromiseBoris** campaign at: **keepyourpromiseboris.com**

Colostomy UK produce two booklets for carers:

- 'Caring for a person with a stoma'
- 'Caring for a person with a stoma and dementia'

You can view these on our website, or we can send you a copy. We also deliver training for carers via our Care Workshops: **www.colostomyuk.org/information/information-for-carers**

World Digestive Day 29 May 2021

We decided to support the day by holding our first Webinar. Colostomy UK President and Consultant Colorectal Surgeon Ian Daniels, and Consultant Dietitian Sophie Medlin joined us for a discussion all about digestion.

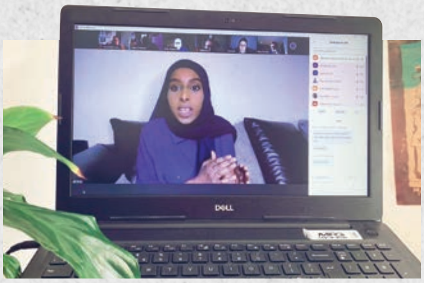
It is very common for ostomates to gain weight after stoma surgery and experience other issues relating to digestion. These two experts came together to discuss optimising digestive health after surgery and maintaining a balanced diet, as well as answering questions in our 'Q and A'. This interactive event was incredibly informative, and we are thankful to both Ian and Sophie for their support. If you would like to listen to an audio recording of the event, visit: www.colostomyuk.org/wp-content/uploads/2021/06/World-Digestive-Day-Webinar-Audio-2021.mp4

To find out more from Sophie, visit citydietitians.co.uk

What is 'Stoma Aware' training?

In March we delivered 'Stoma Aware' training to Hidden Disabilities Sunflower Scheme Ltd.

Our trainers were Colostomy UK Ambassador and ostomate, Ifrah Mohamed (Iffy), and our General Manager Libby Herbert. Ruth Rabet, who attended said: 'Thank you so much for your training session, the whole team found it so informative, and Iffy is incredible, what an amazing lady.'



Colostomy UK has been delivering Stoma Aware training for some years. The aim is to educate about the needs of ostomates, and the nature of hidden conditions. We also talk about 'stoma stigma'. By acting as a 'critical friend' the idea is to support organisations to change their policies and procedures and overcome institutional prejudice.

Often organisations approach us for training, especially if they have an employee who is undergoing stoma surgery. Sometimes training happens after an ostomate contacts us to report a negative experience. This was the case with Blake Beckford. He was humiliated when his colostomy bag leaked on his way to a meeting. He rushed into a nearby conference centre to use their toilet, but even after explaining he had a medical condition the receptionist refused him access, saying they weren't for public use. Blake said this experience made him worried about leaving the house. We ran Stoma Aware training with the conference centre concerned. We have also supported airports, supermarkets, law firms and factories.

If you have a bad experience or know an organisation that would benefit from Stoma Aware training, email **info@colostomyuk.org.**

The British Healthcare Trades Association – Patient Panel

The British Healthcare Trades Association, who represent Dispensing Appliance Contractors (DACs) in England, are setting up a patient panel to gather feedback on the services patients receive from DACs and Pharmacies.

The panel will consist of 300 patients from across all areas of England who have had a stoma for at least 12 months and are willing to submit feedback via an online form four times a year.

The survey will consist of two parts. The first covers requesting appliances. The second is about their delivery by the DAC. Each survey response will take no more than 10 minutes to complete and submit. To take part, your name and e-mail address will be required. A member number will then be created from this and used as a reference during the survey period. Your supplier will not be able to identify your personal responses. All comments you make will be included in the feedback report, but all attempts will be made to remove information that could identify you.

The questionnaire process will be operated by CFEP UK Surveys, a company that is fully registered with the Information Commissioner's Office (registration number Z9673302) and is governed by the Data Protection Act 1998 and the EU General Data Protection Regulation 2018 (GDPR).

CFEP UK Surveys will only be provided with your name and email address for the purpose of this survey and will not have access to your medical details. Following completion of the panel exercise, your records with CFEP UK Surveys will be deleted in accordance with Data Protection and GDPR regulations.

You can register to take part through the following web link cfep.net/wKx3LR. Once the panel is in place, you will be contacted with further information on the survey objectives and process. The aim is to conduct the first survey September 2021.

Have your say!

There is still time to do our survey. As part of our commitment to be the voice of ostomates, we are investigating the service provided by companies that manufacture and deliver stoma products.

We want to ensure ostomates get the best support and services possible! Complete our short survey online at: **www.surveymonkey.co.uk/r/5WMVKCW**

Caring for a person with a stoma – We're recruiting

We're looking for a practising or retired stoma care nurse to support the delivery of our 'Caring for a person with a stoma' workshops in the Home Counties.

Our workshops provide professional and unpaid carers with guidance and practical advice in stoma care.

For further information e–mail: **Giovanni.cinque@ColostomyUK.org**

Colostomy UK

Looking for online support?

Our private Facebook group 'Colostomy UK Support Group' has over 9,000 people and it is a safe community in which you can find support from others living with a stoma. It's not just for those with a stoma; friends, family and healthcare professionals are welcome too.

There is plenty of support available via our website, **www.ColostomyUK.org**. Not only is there a wealth of information, we also have **'Live Chat'** support available 09:00–17:00 on weekdays.

Don't forget, if you can't find the support you need online, you can call our Stoma Helpline **(0800 328 4257)** 24-hour a day.

www.ColostomyUK.org

Find us on **Facebook**


LARGER
VIEWING
WINDOW

Will you Step Up for Stomas in September?

Colostomy UK are going to 'Step Up for Stomas' and we would love you to join us! We're inviting you to walk, run, jog, skip, crawl or hop 160,000 steps in the month of September to help you get more active, and to raise funds.

The money you raise will help us to keep on supporting ostomates and those who care for people with stomas.

Why 160,000 steps we hear you ask?

There are 160,000 people in the UK with a stoma and you will be taking a step for every single one of them. You can undertake the challenge on your own or combine your steps with others to form a team and reach the target together. It doesn't matter if you're active already or just looking to get fitter.

Either way, taking our Step Up for Stomas challenge can only be a good thing! To cover 160,000 by yourself, you need to do about 5,300 steps or about 2.5 miles a day, which equates to approximately 50 minutes of walking or 30 minutes of running.

Step Up for You

It's no secret that exercise is good for both your physical and mental health. Walking can help your mental health by reducing anxiety, depression, and a negative mood. It can also boost self-esteem.

Walking and running are some of the easiest ways to get more active and become healthier and you don't need lots of equipment or a gym membership! As long as you have a trusty pair of trainers or walking shoes, you can Step Up for Stomas and start getting fitter. The NHS states that adults should do some type of physical activity every day. Any type of activity is good for you and the more you do the better. Moderate aerobic activity such as a brisk walk can:

- Burn calories
- Lower your blood sugar
- Ease joint pain
- Boost immune function
- Boost your energy levels
- Improve your mood
- Strengthen the heart (walking at least 30 minutes a day, five days a week can reduce your risk of coronary heart disease by up to about 19%)

Step Up for Ostomates

Colostomy UK is a self-funding charity so every £1 we raise really matters!

As part of this challenge we would love it if you could try to raise £160 or more.

All funds generated will go towards supporting our key projects and services including our 24-hour Stoma Helpline, our new befriending service, and the continued production of Tidings magazine. It will also allow us to train more volunteers, encourage more ostomates to get active, and help us to campaign for a more stoma aware United Kingdom.

The money you raise will help us to support people like Tom:

"Colostomy UK was there for me when I was recovering from my stoma surgery and I felt totally isolated. I didn't know anyone else with a stoma and I didn't know how to manage it - physically or emotionally. They helped me to come to terms with my stoma and eased my anxiety - putting me in contact with other ostomates. The charity helped me to get my confidence back so that I could return to work and socialising."

Kickstart your fundraising!

Whether you're walking, running, jogging, skipping, rolling or crawling your way to 160,000 steps, the money you raise will help us to keep on supporting ostomates and those who care for people with stomas.

You can set up your Step up for Stomas fundraising page on Just Giving, Virgin Money and/or Facebook - you can also print and use the sponsorship form overleaf (page 13).

Just Giving, follow this link:
bit.ly/3zXLUEP

Virgin Money Giving, follow this link:
bit.ly/3xkYU5s

Facebook (during September only) just go to: **https://www.facebook.com/colostomyuk** look for the *'Create a fundraiser'* page, and click on the link.

Fundraising Top Tips

Set a target

Fundraising pages with a target are 75% more successful than those without one! We recommend setting your initial target at £160. If you meet this target before completing the challenge you can of course increase it! This will also give you some good news to share with your friends, family and colleagues to inspire them to donate.

Seed donations

Pages with a few donations give potential donors confidence, lend legitimacy to your fundraiser and encourage further donations. If you can afford to, then put an initial donation on your page and approach two or three people personally to ask for donations before you share your page with the rest of the world.

Shout on social!

Tell people what you're doing on social media and don't forget to tag us in! Your friends and family will be proud of you for undertaking this challenge. Each share could encourage another person to donate (or get active). People often need to see an ask a few times before they donate.

Post on Facebook, Twitter and Instagram and put your fundraising link in your page's profile, bio or status. Check out our social graphics, tell people why raising money for Colostomy UK is so important to you and keep your pages updated so people can follow your journey.

Match funding

Some companies offer to match charity donations up to a certain amount. This can come in the form of a one-off donation, or even go as far as matching everything that you raise. If you're an employee, why not ask if your company will support you?

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Frequently asked questions

Do I need to prove my steps?

This is your challenge so you don't need to send us proof of your completed steps. We do, however, recommend posting progress updates on your fundraising and social media pages to let all your friends and family know how you're getting on with your challenge.

What happens if I miss a day?

Don't worry if you miss a day, it's up to you how you complete your steps. If you miss a day, you could always make up the steps across the next week.

What happens if I don't hit my step goal?

We understand if you're not able to hit your step count in September. Don't panic if you need to put your challenge on pause or you're unable to complete your daily steps. You can simply resume the challenge once you are able to, or you can team up with friends, family or colleagues to complete your steps together. We can't thank you enough for your support.

I use a wheelchair, how can I count my steps?

If you use a wheelchair you could set a target of 160,000 pushes, or use an odometer to track distance then convert to steps. 1km is about 1,250 steps.

I want to swim the challenge, can I do this?

Yes you can! Just track your distance and then convert it to steps. 1km is about 1,250 steps.

Local press is always looking for interesting stories, contact us if you'd like support in putting an article together or if you'd like a copy of our Colostomy UK press release. We're here to support you - if you need anything email Fundraising@ColostomyUK.org.

For more information about Colostomy UK and the vital work we do supporting, empowering, and advocating for people living with a stoma (ostomates), please visit:
ColostomyUK.org
or call 0118 939 1537.

Sponsorship Form

Date of event:___________________________ Sheet number: _____ of _____.

We wish you every success with your fundraising activity. Please remember to return this form to our office with any money raised, otherwise we will be unable to claim gift aid. The donorsa full name, address and postcode are needed in order for us to claim gift aid. You have a legal responsibility to ensure all sponsor money is paid to the Colostomy UK. Please print another copy of this form and number it, if you need additional pages. Cheques should be made payable to Colostomy UK.

Title	First Name	Last Name	Address	Postcode	Amount	Paid	Gift Aid*
MR	JOHN	SMITH	1 EXAMPLE ROAD, EXAMPLE STREET, READING, BERKS	AB1 2AB	£25.00	YES	YES

*I want to Gift Aid my donation and any donations I make in the future or have made to Colostomy UK in the past four years. I am a UK tax payer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of the Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference (currently 25p for every £1 donated).

Colostomy UK

Every 39 minutes someone in the UK has stoma surgery.

Help us to support them.

Donate now.

Cheque, standing order or direct debit: please see the donation form on page 27.

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

By text: To donate £5 on your mobile device please text TCUK to 70970. To donate £10 text TCUK to 70191.

Thank you for your support.

Text donations will be processed and administered by the National Funding Scheme (Charity No: 1149800), operating as DONATE. Texts will be charged at your standard network rate. For Terms & Conditions, see **www.easydonate.org**

Colostomy UK

#ActiveOstomates

active ostomates®

Support from the National Lottery Community Fund

In May we received a significant grant from the National Lottery Community Fund to support our planned return to delivering Active Ostomates classes through stoma support groups in 2022.

If you run a stoma support group and would like to arrange one of our classes when your face-to-face meetings re-start, please get in touch with me at Giovanni.cinque@ColostomyUK.org

This autumn, we're also delighted to announce the return of Active Ostomates: at Home, with virtual yoga, art, Mindfulness and Meditation, Pop To and Zumba classes. To keep up to date with the latest news on classes and other events please visit our Active Ostomates pages at colostomyuk.org/active-ostomates/

Rugby League is back!

By the time you read this our Rugby League team, Team Colostomy UK will have played their first game since the end of 2019 thanks to a pandemic–forced hiatus.

On 14 August an exciting triple header in Maidstone, saw a mixed team (male and female!) of ostomates, family members, and friends take on the Invicta Panthers Masters team and Robbie's Roos who play to raise funds and awareness for the charity 'Say Goodbye'.

The team is back in action again on 11 September, when they travel to Chorley Panthers in Lancashire. For more information on the game please visit colostomyuk.org and search 'Rugby League' or follow the team on Twitter or Instagram @teamcolostomyuk.

Active Ostomates at Home, There's something for everyone

The last eighteen months have been tough for many of us including those who like to keep mentally and physically active. We introduced our Active Ostomates: at Home classes in May last year to provide an outlet for ostomates during lockdown restrictions.

We're really proud of the impact our classes have had on so many people. Here Sarah and Brian tell us how they've benefited from Mindfulness and Meditation, and art activities.

Sarah's story

In December 2019 I was shocked to discover I had ovarian cancer. I had a 20cm growth and the cancer had spread to my bowel.

My operation took place in February 2020. I had a full hysterectomy and the ovarian tumour removed, along with part of my bowel, resulting in an ileostomy.

I was due to receive my biopsy results in March 2020 just as the country went into lockdown. This meant that I had to hear some difficult news over the phone. My surgeon informed me that I had stage 3C cancer and it had spread to the bowel and lymph nodes. It is a very rare type of cancer (mucinous ovarian), which is not sensitive to chemo… so the plan was watch and wait.

I was/am determined to beat this and get well. I immersed myself in daily exercise and eating incredibly well. What I didn't do was look after my mind. Luckily, my Macmillan nurse picked this up and referred me to a psychologist. These sessions have helped with acceptance and I am learning to be kind to myself.

Giovanni Cinque
Fundraising and Development Manager
E: Giovanni.Cinque@ColostomyUK.org

I am quite savvy with Twitter and luckily started to follow Colostomy UK. I saw the advert for Active Ostomates and thought… why not! I have tried meditation a few times and have found it tricky so I was skeptical and a little nervous about the first session.

For me the sessions have been incredible. I feel it is my safe space and a real time when I allow myself to focus on me. Sophie our teacher is excellent, she has the most soothing voice and I love how she gets us to check in with our minds but not to get stressed if our minds are racing that day. She also focuses on our tummies, which allows me to give a nod to my stoma and a period of gratitude as it is probably part of the reason I am still alive.

I get so much comfort knowing that I am 'virtually' with other ostomates, all with one thing in common: a stoma! I always feel so refreshed after Sophie's sessions. I feel like I have had a day at a spa. I am so glad that Colostomy UK have extended their sessions.

Due to being a head teacher and making the decision that I needed to take some time away from school after being diagnosed in December, lockdown since March has not felt too different. I have felt like I have been in lockdown since December. The Active Ostomates sessions have helped me so much mentally and allowed me to feel connected to others even though having to shield made me feel so isolated at times.

Sarah's' name and image changed
to ensure anonymity

Brian's story

There are so many things I can't do that I've always wanted to. I can't swim, although I've always lived by the sea. I can't mimic accents. I don't understand chemistry or physics. Definitely not physics.

There's been one other thing that I've never been able to do, and that is to paint or draw. When Colostomy UK advertised their online drawing classes I didn't think it was for me. But then I spoke to a good friend who pointed out that classes are generally for people who think they can't do something but who want to try and see. So, I signed up.

And boy, I'm glad that I did. It's been absolutely fantastic. A great experience. There have been so many great things about it. Top of them all is the amazingly skilful tutor, Louise Bradley. She set us out with several warm–up exercises to get used to the feel of the paper and the pencil (Oh! That's another great thing about it. The only tools that are essential are a pencil or biro, an eraser and A4 paper. We did do one session on charcoal drawing, but again a pencil would have worked).

One of the things Louise taught was to try not to look at the paper when you're drawing. Just let it be fluid. That's hard. But the more I tried the easier it got. There was no pressure whatsoever to share your masterpieces if you didn't want to.

We started out drawing plants, or bits of plants. Slowly Louise brought more techniques for us to try out. How to use your pencil to measure. How to work out perspective, details like shading, cross hatching (I know, sounds like I know what I'm talking about, eh?)
and the use of shadows.

The course was for four sessions initially. But then a further course was commissioned by Colostomy UK. This one was on faces. We started off with pictures of upside-down faces, to get us to think of the shapes, rather than to merely attempt to copy. Absolutely fascinating.

In these classes I feel that I've come across a mystery Hebridean island that few people know about. It's been adventurous and fun, especially during this whole Covid thing. It's been nice to talk to friends, old and new. I still wouldn't say I'm very good at drawing. But that's not the point. The point is about expression and believing that I have a right to try.

And the other good news? Colostomy UK have commissioned another series of lessons. They really have been very good to us. Very sensitive and kind. Thank you to them all and to our wonderful, skilful, encouraging and patient tutor Louise. I'm lining up my pencils, ready for the next course."

Our Active Ostomates: at Home classes really do have something for everyone. If you're looking to keep active or take up a new activity without the hassle of leaving home, please look at our current classes through the link in the latest news section.

Christmas cards

Spread the festive cheer this winter with our Colostomy UK Christmas cards. These biodegradable cards picture a quintessentially English village snow scene, with a classic red post box and robin. The message inside reads "With best wishes for Christmas and the New Year". Our cards come in packs of 10 and 100% of profits from every purchase goes towards helping ostomates.

So, make someone feel special this Christmas by sending them a handwritten card and support Colostomy UK at the same time.

Order form

Colostomy UK Christmas Cards (pack of 10 biodegradable cards with envelopes) £4.50

Postage and packaging

Please add the following contribution for card orders of:

Orders up to £5 - £1.50

Orders between £5.01 & £10.00 - £2.95

Orders between £10.01 & £20.00 - £3.75

Orders between £20.01 & £50.00 - £4.95

Orders in excess of £50.00 - £6.50

Number of Packs

Sub Total - £ ____________

UK P&P - £ ____________

giftaid it **Donation (optional) - £** ____________

TOTAL - £ ____________

Personal details

Title: ____________

Name: ____________

Tel: ____________

Email: ____________

Address: ____________

____

____________ Postcode: ____________

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

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

Paying by cheque

Cheques should be made payable to Colostomy UK and sent to:

Colostomy UK, PO Box 280, Weston super Mare,
North Somerset BS22 9ZD

Paying by card

Card number: (Meastro only)

☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐

Expiry date: ☐☐/☐☐

Security code: ☐☐☐

Start date: (Meastro only) ☐☐/☐☐

Issue No. (Meastro only) ☐☐

Signed: ____________

Dated: ____________

Gift Aid Statement:

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 purchase 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.

Finding someone to ‘really’ talk to after emergency stoma surgery

WRITTEN BY
RICHARD BIDDLE

When Eric Douglin told me about how he underwent emergency stoma surgery during lockdown and then struggled mentally afterwards, it made me very sad. This was partly because I could personally relate to aspects of his experience. Having wrestled with mental health issues myself for well over a decade, I recognised all too well some of the feelings and emotions he described. But this wasn’t the only reason. It was also because, in a strange kind of way, I felt partly responsible. Hearing Eric say that his sense of isolation was compounded by not being able to find someone to ‘really’ talk to, confirmed something I already knew, but felt powerless to address: that when it comes to pre– and post–operative support, some patient groups are less well catered for than others. Hilary Kennard’s article (pages 45-47) highlights school-age children as one group. Eric is an exemplar of another. Put simply, Eric is black.

Eric, who is 58 years old and works as a cyber security analyst for Direct Line Insurance, was no stranger to serious illness when he had his ileostomy in January this year. Back in 2010 he had a kidney transplant (his wife Mandi was the donor) to treat chronic kidney disease. The difference this time was the speed with which things happened. When Eric started to experience stomachache on New Year’s Eve, his initial thought was over-indulgence during the Christmas period. Three days later, a surgeon at the Prince Royal Hospital, Orpington, was telling him:

> “We have to operate immediately or you could die in 24 hours.”

Eric’s memories of this moment and afterwards are vivid. What he had gone on to think was probably food poisoning or an appendicitis, turned out to be a tear in his intestine caused by diverticulitis. A bowel resection was therefore urgent, because of the risk of septicemia. Shocked, and in terrible pain, Eric signed the consent forms and then phoned Mandi with the news (Covid-19 restrictions meant she couldn't be there). He can still hear her crying now. Eric was then whisked away under blue lights to Guy's Hospital. Being a kidney recipient, it was felt it was safer to operate here, where there is a specialist renal unit, just in case there were any complications. It was an unwelcome development for Eric. Returning to the hospital in which he had his transplant brought back the memories of this period. It also fed his growing sense of desperation placing him, as it did, far from his family. He remembers thinking how he didn't want Mandi's last memory of him to be one of a man doubled up in pain. Scared and bewildered, Eric faced his Hartmann's procedure alone, not even really knowing what a stoma was.

Eric woke to hear everything had gone well and, as only a few inches of bowel had been removed, a reversal would be possible later done the line. One would think that such news would be consoling, but Eric didn't find it so. He was shocked at the sight of his stoma and the way his body now functioned. He started to think of himself as some sort of freak and doubted how his wife would ever find him attractive again. Eric also started to worry about the future, and whether the long walks he enjoyed and the *basketball** he loved to play were now a thing of the past.

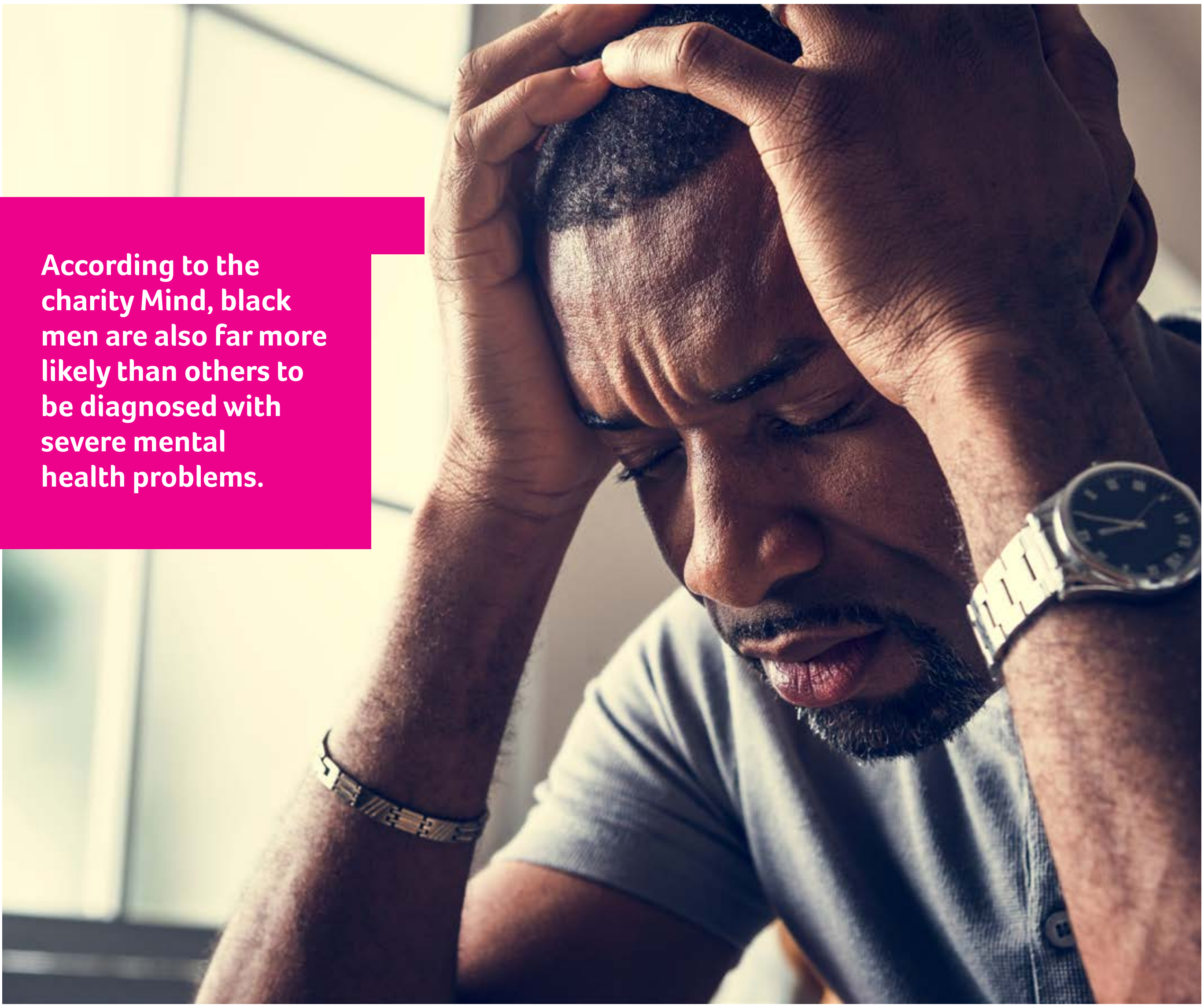
*Eric is founder of the World Club Basketball Tournament

Eric's mood darkened further when he was put on the same ward as he had been on a decade ago. Plagued by these thoughts, he spent a difficult week or so in hospital, made all the more challenging when he developed sepsis and then succumbed to Covid-19. He also had to cope with knowing that his son, who is a young father of three, had been hospitalised with Covid-19 too.

Given all he had been through, along with the added worry of his son's health and feeling powerless to do anything to help, it is not surprising that Eric's mental health took a severe knock. He experienced a range of emotions, from anger (Why me? What have I done to deserve this?) through to despair (How can I ever cope with life?) and finally guilt (What's wrong with me? Why am I being so difficult with everyone?).The process of recovery and healing then began. Having been through transplant surgery, the physical side of this held few surprises for Eric. As he expected, progress was slow, with a gradual lessening over time of the pain and discomfort. The mental side however, he found especially challenging. His mind took longer to heal than his body. When I asked Eric what had helped, he answered quickly: time; the unwavering support of his wife and family (which includes five grandchildren: two teenagers and three that are smaller); and doing lots of research about stomas and diverticulitis. This research helped him to realise that he was far from alone.

So where then, does the colour of Eric's skin come into this story and the rather bold claim I made at the start, about certain patient groups being less well supported than others? In talking to Eric, it quickly became apparent that the statement he made about not being able to find someone to 'really' talk to, was the articulation of a much broader issue. It's also an issue faced by healthcare professionals and charities alike: How do you reach and support people from different cultural and ethnic backgrounds? What Eric craved was to speak with someone from the black community who had a stoma. The problem was he couldn't find anyone as he set about researching his condition. The more we talked, the more it became clear that this was a problem that wasn't going to be solved by simply putting more pictures of people from the black community on support literature or in advertisements for stoma care products (although this would help). It is far more complex than that.

As a peer-to-peer educator with the organisation Gift of Living Donation (GOLD), where he provides guidance and support for organ donors and recipients from the black community, Eric is well placed to understand the challenges. As he explained, black people have different family orientations and outlooks, which can make them suspicious of people from outside of their communities. If that wasn't enough, Eric also pointed out that black men in particular regard admitting to being ill (mentally or physically) and seeking help or any form of treatment, as a sign of weakness.



According to the charity Mind, black men are also far more likely than others to be diagnosed with severe mental health problems.

He said this cultural norm is so pervasive, that he has personally known men who have doomed themselves to a life of suffering with chronic illness and, ultimately, an early grave. According to the charity Mind, black men are also far more likely than others to be diagnosed with severe mental health problems.

The consequences of all this are twofold. Firstly, it makes people from the black community hesitant about sharing their stories. As the editor of Tidings, I am frequently told by readers how our 'Real Lives' stories have helped them both before and after their stoma surgery. Secondly, it can make black people reluctant to put themselves forward as volunteers willing to talk with new patients.

Peer-to-peer experience-based support of this nature is of course fundamental to what Colostomy UK does.It is also proven to work. Indeed, we were founded half a century ago on the back of a successful volunteer ostomate hospital visiting scheme, piloted with new patients in the colorectal ward of a London hospital. Of course, none of this ruminating helped Eric in his time of need. Clearly the magnitude of the problem is such that solving it will require not just time and determination, but also a range of approaches and measures. It will require charities, healthcare professionals, community leaders and patients alike all taking responsibility and working together. It will also need courageous people like Eric.

We shouldn't underestimate the importance of him sharing his story. Not only does it have the potential to help those who read it, but it just might also encourage others to come forward and do the same. Small starts often lead to bigger things.

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fundraising

Giovanni Cinque
Fundraising and Development Manager
Giovanni.Cinque@ColostomyUK.org

Supporting Colostomy UK

As a self-funding charity, we rely on your fundraising and donations to fund all our services and campaigns, including your copy of Tidings, so every £1 you give really helps!

There are loads of ways you can support us. Please visit **www.colostomyuk.org/get-involved/fundraising** for more details on how you can make a difference.

Everyone has their own story to tell
In this edition we're going to tell the stories of five individuals and the personal challenges they have taken on to support Colostomy UK.

Alan Ritchie

On Saturday 8 May, Alan Ritchie walked between Charing Cross and George Square in Glasgow with his shirt off so the world could see his stoma bag. It was his way of tackling the stigma that still exists in society around stomas. He also wanted to raise funds for Colostomy UK.

He managed to raise over £1,100 and received some great media coverage including the Daily Record, Glasgow Live, and the Glasgow Times.

Alan has Diverticulitis - a condition that causes small, bulging pouches to develop in the digestive tract before becoming infected. He had stoma surgery in July 2019 and struggled to come to terms with life afterwards. Complications from a planned reversal left Alan with a permanent stoma. He spent six weeks in intensive care and at his lowest struggled to see a future for himself. However, with the support of his fiancé and father (who also has a stoma) Alan slowly turned things around.

Taking on this challenge was Alan's way of showing to himself that he has accepted who he is. As he told the Daily Record:

"I just believe you can still be beautiful, and you can still enjoy yourself. I didn't think I would find a normal life, but you can. I was really low and didn't think it was possible, but I have."

You can still donate to Alan's GoFundMe page: **gofundme/3d5535c8**

Manesha Chauhan

Manesha's story is very different to Alan's. She doesn't have a stoma but was inspired to run in the HollyBank Eccup 10 Mile on 27 June because of the support the mum of a close friend received from Colostomy UK after stoma surgery.

In Manesha's words:

"My close friend Rhicha Kaplia is a great supporter of Colostomy UK because of the support they gave her when her Mum was fitted with a stoma.

Because it means so much to Rhicha and her family I would like to also support the charity and raise funds."

So far Manesha has raised a brilliant £395 and there's still time for you to donate to her fundraising page: **www.justgiving.com/fundraising/maneshachauhan**

The spring edition of Tidings features an article from Manesha's friend Rhicha, where you can read more about her mum and the support she received.

Emma Raynes

45-year-old Emma was diagnosed with Crohn's Disease at the age of 26. Since then, she thinks she's clocked up close to twenty appointments to the surgeon's table.

Emma took up running in October 2018:

"Not just because I wanted to show Crohn's who was boss, but also because in the past I have suffered from Post-Traumatic Stress Disorder (PTSD). Exercise is so good for the mind; it has allowed me to heal and grow. Since then I have taken on many challenges running 5k, 10k and half marathons. I am extremely resilient, and this is my major strength. I have pushed myself regardless of the disease I am living with so I can get to the finish lines and to complete other challenges such as mountain walks."

This July Emma took part in the Chester GB Ultra 50 Mile challenge for Colostomy UK, raising funds to help us *"raise awareness and support everyone with Crohn's Disease and a stoma"*. Emma's Just Giving page is still open and you can support her here: **www.justgiving.com/fundraising/emma-raynes12.**

Stamps to be cut/torn from recent mail.

- British and foreign stamps – no need to separate.
- No more than 1cm of envelope left around each stamp.
- Do not trim stamps too close so that perforations are damaged.

You can now donate your used and unwanted stamps to Colostomy UK, send to:

Colostomy UK Stamp Appeal
10 Chestnut Avenue
North Walsham
Norfolk
NR28 9XH

Quarterx1 01v00r00 Stamps | Date of Publication: June 2021 | Copyright ©2021 Colostomy UK | Registered charity no. 1113471

Picture perfect

Talented artist, ostomate, and supporter of Colostomy UK, Emily Hackworthy has created a beautiful and striking set of 'outline body' prints representing ostomates.

Her artwork of male and female forms with either a colostomy or ileostomy are now available for sale via our online shop, and Emily is kindly donating all the proceeds to Colostomy UK.

You can order online at:
https://colostomyuk.bigcartel.com

Please allow 28 days for delivery. Purchase is for print only. Frame not included. Print size A4.

Donna Acheson

Donna is bravely taking on a '365 sea swim challenge' - to swim in the sea, without a wetsuit, every day for one year.

Donna was rushed to hospital two years ago due to complications with her bowel and ended up having stoma surgery.

Donna recalls how:

> ***"The [experience] had a huge negative impact on my mental health, which I had been suffering from for some time. Thankfully, Colostomy UK and their Facebook support group have helped me by exposing me to other individuals who are also living with stoma bags and the stories surrounding their recovery"***

You can support Donna through this link: **gofund.me/fe7ec365**

Legacy

Leaving a gift in your will to Colostomy UK will make a real difference to the support we are able to give to the ostomates of today and tomorrow.


Colostomy UK

Help us support the ostomates of today and tomorrow

Will you consider leaving **Colostomy UK** a gift in your Will?

If you'd like further details on leaving a gift to us please call **0118 939 1537** or email **fundraising@colostomyuk.org**.

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 25) 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 fundraising@colostomyuk.org

☑ giftaid

Colostomy UK

Advertorial

CONFIDENCE BE®
MY PROFESSIONAL PERSPECTIVE

Catherine Brooks is a Senior Specialist Stoma Care Nurse with extensive experience of helping people on their stoma journey. We asked Cat for her professional perspective on how nurses guide people through a difficult part of their lives and find the best solutions for each individual.

WHAT FACTORS DO YOU CONSIDER WHEN CHOOSING THE RIGHT PRODUCT FOR EACH PATIENT?

Everyone is an individual, so I need to find out about them – their lifestyle, their work and preferences. I always outline a range of options and suggest the latest products because they will include the most up to date designs and have been developed using patients' insights.

WHAT FACTORS DO YOUR PATIENTS LOOK FOR IN PRODUCT CHOICE?

Functionality, confidence in it working and how it looks and feels. Patients want reassurance that it will be **safe and secure,** with **no leakage**. Or what it feels like to wear. Also, how it will look; quite rightly some people are self-conscious. People want to **be confident** that the bag won't get noticed, that it will blend in with their clothing.

> *"We recommend Confidence BE® to help improve patients' lives."*

Watch Catherine's #MyProfessionalPerspective video at www.salts.co.uk

WHAT ARE YOUR PATIENTS FIRST IMPRESSIONS OF CONFIDENCE BE®?

Unlike some products, Confidence BE® **doesn't look or feel like a medical device,** it's discreet and looks just like a piece of clothing. This is really reassuring for new patients who may not have a clear outlook of what is a stoma. Many existing patients see new products on social media and want to try something new. They are attracted to the **choice of three colours** and its ability to co-ordinate with their look.

CAN YOU GIVE AN EXAMPLE OF THE POSITIVE IMPACT CONFIDENCE BE® HAS HAD ON A PATIENT?

I had a guy in his early 20s, early post-op, visit me wearing an old-fashioned, large clear product. I immediately asked him why he chose it. He didn't realise there was product choice! It was too big, visible under his t-shirt. Being clear the discharge reminded him he wasn't well. I showed him Confidence BE®. He liked the fabric, the black colour, the **easy opening,** the fact he didn't see anything. He felt it would fit in with his clothing especially when down the gym. He was sporty and loved its **waterproof filter.** After wearing Confidence BE® you could see the difference – the product change gave him a lift... it really gave his recovery a boost.

WHAT IMPACT HAS CONFIDENCE BE® HAD ON THE STOMA CARE MARKET?

It made a huge impact. At the time of launch the market was full of new **innovative** products but Confidence BE® went above and beyond because it addressed all aspects from the patients' perspective. Choice in colour, fabric materials, **noise reduction, ease of use**. I remember my colleagues and I had a list of patients we wanted to recommend it to help improve their lives, because that is ultimately our goal.

Confidence BE® closed and drainable bags are available in black, white and stone

salts HEALTHCARE

For samples or more information,
freephone **0800 028 2144** (UK), email **samples@salts.co.uk**
visit **www.salts.co.uk**, follow @SaltsHealthcare

CONFIDENCE BE®
For all you want to be

Emma Howell
Volunteers Manager
Volunteer @ColostomyUK.org

volunteers

Alfred Levy steps down as a trustee

We are very fortunate at Colostomy UK to have volunteers from all over the country, willing to share their experiences as ostomates for the benefit of others. They also bring with them a whole range of other skills and experiences, all of which are invaluable too.

As you may have noticed, this copy of Tidings has two stories written by volunteers on the editorial board. Each story was then proof-read and corrected by another volunteer! Colostomy UK's Board of Trustees is also comprised solely of volunteers. Some have qualifications in, for example, human resources, and finance.

This edition's volunteers' page is dedicated to Alfred Levy, who is retiring as a trustee. He will be continuing to volunteer for us in other aspects of Colostomy UK's work. Alfred had a colostomy in 2006 as a result of bowel cancer. He became one of our volunteers five years later, shortly after retiring as a chartered accountant. In the decade he has been with us, Alfred has done everything from taking calls on the Stoma Helpline to attending open days on our behalf. However, with his background in accounting and finance, he had the necessary skills and experience to be our Treasurer and Finance Trustee. He took on this role in April 2013. Soon after, he added to his responsibilities by joining our management committee, who tackle the operational issues we sometimes face.

Mandi Laing our current chairperson had this to say:

'I would like to say a personal thank you to Alfred. When I joined the board he was welcoming and friendly and he continued in this vein throughout the entire time we sat on the board together. He has always had the best interests of Colostomy UK at the heart of everything he did for the charity and with this objective in mind was a huge support to me, Libs and the team, and the new trustees as we rebuilt the board over the last two years.'

While a trustee, Alfred also worked tirelessly for ostomates in his local area. In 2011 he set up a support group in Stevenage, called 'Ostomistics'. Today, the group has over 178 members and pre-COVID-19 was meeting 12 times a year.

Judy, who is one of our volunteers and also involved with Ostomistics said:

'Alfred soon realised there was so much more he needed to know and his surgeon said there were many in Stevenage in the same position. It was then he thought a support group might be the solution for people with a stoma whether it was a colostomy, ileostomy or urostomy. In 2011 after much perseverance and against all odds Alfred succeeded in starting Stevenage Ostomistics which has gone from strength to strength. He kept the group going via Zoom meetings during the pandemic.'

Throughout his long association with Colostomy UK Alfred has gone out of his way to support people with stomas, whether they were in that difficult post-op period or further down the road. That's why we are sorry that he is retiring as a trustee but relieved that he is staying on as a volunteer!

Please support Colostomy UK

Your donation to **Colostomy UK** will make a real difference and help us to better support more ostomates like you. Please consider supporting us by donating, or setting up a regular standing order or direct debit (see reverse page). Thank you.

Please complete in BLOCK CAPITALS

Colostomy UK

My Details: Title*: First name*: Last name*:

Address*:

Postcode*: Phone Number:

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

Date of birth: Date of surgery:

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

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.)

ONE-OFF DONATION

☐ £25 ☐ £30 ☐ £50 or 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

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: / / 2021

T63

REGULAR DONATION – Instruction to your Bank/Building Society to pay by Banker's Standing Order:

To the Manager: (Bank or Building Society)

Bank Address: Postcode:

Name(s) of Account holder(s):

Account number: Sort code:

I would like to make a regular donation of ☐ £25 ☐ £30 ☐ £50 or other amount (please state) £

☐ monthly ☐ quarterly ☐ annually starting on the ☐ 1st ☐ 15th of the month ☐ Half yearly standing order, year:

thereafter until further notice. (Please cancel any previous standing order in favour of this beneficiary).

Please allow one month's notice to ensure donation processes through banking system and state your donation amount in words:

Please pay: NatWest Bank, Market Place, Reading, Berkshire, RG1 2EP

Account name: **Colostomy UK** Account No: **88781909** Sort code: **60-17-21**

Name: (IN CAPITALS)

Signed: Date: / / 2021

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, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA.** Telephone: **0118 939 1537** if you have any queries.

Registered Charity No: 1113471

Registered with FUNDRAISING REGULATOR

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Charity Name: Colostomy UK

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

Name and full postal address of your Bank or Building Society

To: The Manager

....

Bank/Building Society

....

Address

....

....

.... *Postcode* ....

Name(s) of Account Holder(s)

....

....

Bank/Building Society account number

Branch Sort Code

Service User Number

6	9	1	2	1	3

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

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

Signature(s)

....

....

Date (DD/MM/YYYY) ....

Banks and Building Societies may not accept Direct Debit Instructions from some types of account

- - - - - - - - - - - - - - - - - - - -

This is not part of the Instruction to your Bank or Building Society

My Details

Name

☐ *Mr* ☐ *Mrs* ☐ *Ms* ☐ *Other (Please Specify)*

....

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Address

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....

....

.... *Postcode* ....

Donation Details

I would like to make a regular donation of £ ....

☐ *Monthly* ☐ *Quarterly* ☐ *Half Yearly* ☐ *Annually Commencing*

01 / ☐☐ / ☐☐☐☐ *or*

15 / ☐☐ / ☐☐☐☐

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Please Gift Aid this donation and any donations I make in the future or have made in the past 4 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.

Please notify us if you want to cancel this declaration, change your name or home address or if you no longer pay sufficient tax on your income and/or capital gains.

☐ *Tick to apply*

T63

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This guarantee should be detached and retained by the Payer

The Direct Debit Guarantee

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

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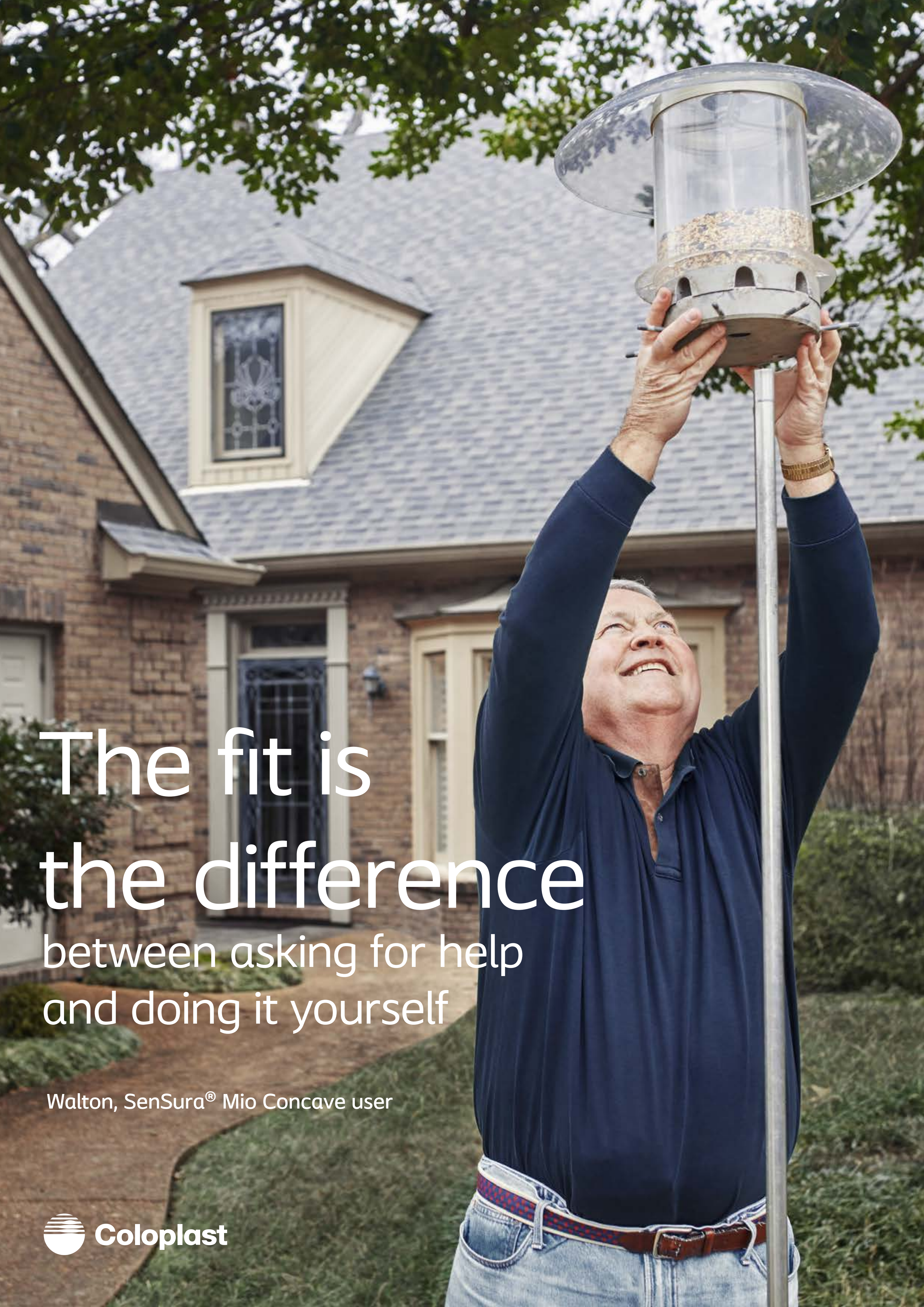
large
Genii Convex Ostomy Seals
small
Genii Flange Extenders
Flat
Genii Ostomy Seals
medium



The fit is the difference

between asking for help
and doing it yourself

Walton, SenSura® Mio Concave user

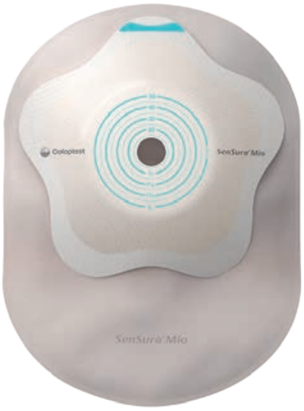
Coloplast

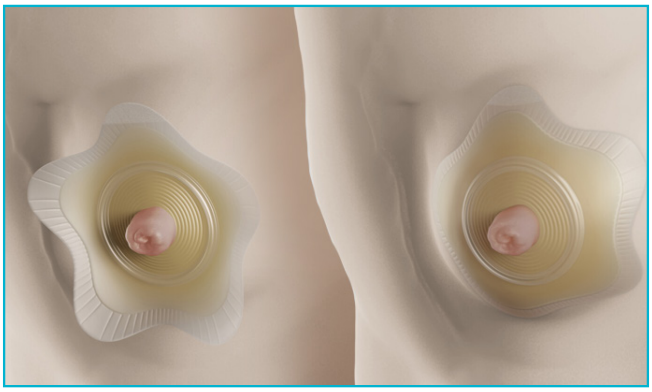
“My body changed, but my stoma bag didn’t. That’s why it didn’t work as well anymore.”

It can be difficult to find a baseplate to fit over curved body areas around the stoma without getting creases and folds. The SenSura Mio Concave has a star-shaped baseplate that is specifically designed to grip the curved area for a snug and secure fit - even when bending and stretching.

Walton first experienced leakage soon after getting his stoma. After surgery, his body shape changed and the stoma baseplate he was using no longer had a secure fit. After trying the SenSura® Mio Concave - designed specifically for curved body profiles – Walton now enjoys peace of mind.

A built in stability ring supports the stoma at the centre of the baseplate while the star shape hugs the body.





The SenSura Mio Concave arrives inverted - a unique design to make the baseplate easier to apply over curved body profiles.

If your body shape has changed recently you may need a different baseplate. Contact us today to see if the SenSura Mio Concave is the right fit for you.

✂ -

*By filling in the coupon, one of our product specialists will contact you to discuss which is the right solution for your needs before sending any free samples. Simply post back to FREEPOST COLOPLAST (no further postal address details or stamp required) and we’ll be in touch.
Alternatively, visit www.coloplast.co.uk/colostomyUK

Request your FREE sample

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Surname ____________________

Date of birth ____________________

Email ____________________

Date of Stoma Surgery ____________________

Telephone No. ____________________

Signature

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Regulated by CareQuality Commission

*Our team are registered with the CQC (Care Quality Commission) who independently regulate the care we provide.

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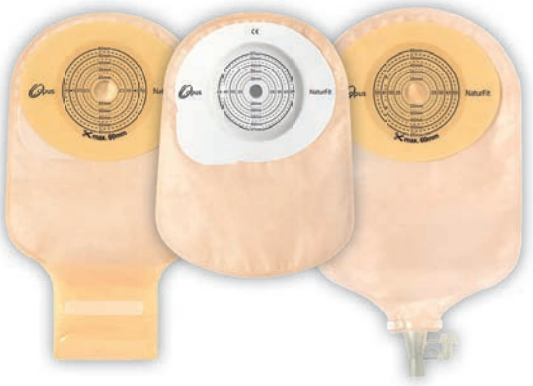
NEW
CONVEX



Getting back on track after surgery

WRITTEN BY
RICHARD BIDDLE

James' talks about his journey after surgery and staying focused on a gentle recovery back to 'normality'.

The urgency to get well after surgery is felt by many. Callers to our Stoma Helpline often ask: 'How long will it take me to recover?'; 'Is it normal to take this long?'; 'Is there anything I can do to speed things up?'. Questions like this aren't limited to new ostomates either. People who have had or are due to have a reversal or perhaps surgery to repair a parastomal hernia ask them too. I also know that in those dark post-op moments some even doubt recovery is possible at all.In the past, Tidings has been criticised for publishing too many upbeat stories, which to me is an indication of just how difficult (and lengthy) the whole business of getting better can be. James Cunliffe had his stoma surgery in March last year. Twelve months later he completed a marathon. Of course, running marathons isn't something most of us will ever do, let alone so soon after major surgery. But when I spoke to James earlier this year, I was struck by what he said about his recovery and the context in which it happened. I believe there is much to learn from his experience.

James is a PE teacher at a secondary school in the Wirral. He is sports mad and admits to being into everything. Bat, ball, you name it, he's interested in it.

Hockey though is his real love. He has played to a decent level (two below premier league) and now coaches the local club team two evenings a week.

James' troubles began five years ago when he was 27 years old. Initially he thought he had a stomach bug. But when the diarrhoea continued for two weeks and he started to feel really unwell, he went to the doctor. His GP ordered blood tests, but before these could be organised James got worse and ended up in hospital. This led to a diagnosis of ulcerative colitis (UC). As regular readers will know, a sudden onset like this is not uncommon. James, who at the time had never been ill (beyond the usual coughs, colds and sports injuries), assumed treatment would be a simple case of taking medicine. This proved so to start with. James enjoyed a full return to health and even got to the point of being weaned off his medication.

Fast forward eighteen months, to the eve of the first Covid-19 lockdown and James' symptoms returned. He can remember it well, because it was a Saturday and the last game of the hockey season. He also remembers thinking it would be treated in the same way as before. After the match he went to A&E and was admitted to hospital. But this time he didn't respond to the medication. By the Friday (the day we went into lockdown) the surgeon had started to talk to James about a stoma. With routine surgery starting to be cancelled, he didn't feel it was safe to wait any longer to see if the medication worked. In his view, should surgery prove necessary, then any delay could have serious consequences. In effect, James was presented with a fait accompli and, just like Sharon Morrin (see summer 2021 Tidings), went through the lonely experience of stoma surgery in a pandemic, where no visits from loved ones were allowed. The only thing that consoled James was the surgeon telling him it wasn't his fault; there was nothing James could have done to prevent his illness.

It is now well over a year since James had his surgery. He is back at work, participating in sports and coaching hockey. He still has some bad days but, with his life finally starting to resemble something akin to normal, he forgets he even has a stoma. When we discussed his journey to this point, four things emerged as key. The first was the support he received, particularly from his family and partner. James' girlfriend is a primary school teacher. This meant she was at home when he was discharged. In the early days this was especially important, as an issue with his wound left James almost bedridden. Having her on hand and willing to help with everything from showering to hair washing proved vital to kickstarting James' recovery. As things improved, his friends became an increasing source of support as well. He went to the pub with some of them six months post-op. Looking back, James struggles to imagine how he would have fared without so many people to lean on. His advice to people in the early post-op period is simple: don't be too proud to ask for and accept help.

The second key thing was information. During the first few months James and his girlfriend devoted time to researching UC and stomas. Although not everyone's cup of tea, for James this included engaging with social media. This is how he found Colostomy UK and became a Tidings reader. James says finding out about his condition was reassuring, and he also quickly learned that he was far from alone in terms of the challenges he faced and the fears he harboured. Importantly, he knew where to get help, whenever this was needed. In other words, the information he found and the people he engaged with, functioned as a source of support too.

Thirdly, James says that he tried to maintain a positive outlook. This was an aspect that we talked about at length, simply because I was keen to learn how he did this. It's one thing to say 'be positive' but quite another to successfully nurture and maintain such a mindset, when you are recovering from stoma surgery. As we know, the mental and physical toll is significant. James thinks his discipline as a sportsman and background in coaching helped. In the sporting world, you focus on the goal (in his case a return to health) rather than how you get there. James applied this to his recovery, which made it easier for him to view setbacks against this bigger picture. In his words: *"I didn't see the point of getting upset."* He says he was also helped by his late nan who imprinted on his psyche that you 'shouldn't feel sorry for yourself'. His sister helped too. As someone with cerebral palsy, she managed to inspire in James a bizarre sense of sibling rivalry, leading him to think *"If she can face this, then I can recover and cope with a stoma!"*

The final, and perhaps most important thing was time. James took his time to recover. Once he started to get more active, he built his levels of activity up slowly and steadily. He didn't return to work for five months. With the running, he began by taking short walks and built on this foundation. He listened to his body and didn't push things. As we talked, it became clear that the pandemic had some unintended, yet positive consequences, for James' recovery too. Being in lockdown and initially falling into the shielding category, cushioned James from the relentless pressure that society can put us under to get well and get back to normal. James describes this as being 'drip-fed back to normal'.

There is no such thing as a textbook recovery. Instead, it is a very individualised thing, depending on all sorts of factors, including health at the time of surgery, type of surgery and medication being taken etc. But, as James' experience shows, there are some things you can do to help recovery. These include accepting support from others, doing your best to develop a positive mindset and, once you start to get active again, taking this (quite literally) one step at a time. James' recovery during the pandemic also highlights the importance of taking your time to recover. Getting better is difficult enough, the trick is not to make it harder by putting yourself under pressure to do so too quickly.

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Colostomy UK

dear nurse

Emma Vernon
SecuriCare Stoma Care Nurse
Email info@securicaremedical.co.uk.

Parastomal hernias and how to manage them

During stoma surgery, the surgeon makes an opening through the abdominal wall to pull a piece of bowel through to make the stoma. This opening can be a weakness within the abdominal wall. The opening may enlarge, allowing intestine, fat or other abdominal tissue to bulge through it and develop a parastomal hernia.

Some people are prone to hernias because they are born with a genetic inability to produce collagen (protein) to repair and strengthen muscle and they may already have a history of hernias in their body. Some people are born with a normal ability to produce collagen, but lose it due to malnutrition, infection, corticosteroid use or smoking.

Reducing the risk of getting a parastomal hernia

The following can not only help to reduce the chances of getting a parastomal hernia in the first place but also prevent existing hernias from getting worse:

- Reduce any form of heavy lifting.
- Perform light abdominal exercises to strengthen the abdominal wall.
- Support the abdominal area with support belts or support garments.
- Try to hold a pillow on your abdomen if you need to cough or sneeze. This supports your abdominal wall and reduces intra-abdominal pressure. A support belt/garment will also help.
- Prevent constipation by drinking plenty of fluids and practice good nutrition with plenty of fibre and bulk in the diet. You might like to consider taking regular fibre or a bulking agent to maintain a regular soft output from your stoma.
- Avoid gaining weight, or try to lose weight if you need to.

What can you do if you have a parastomal hernia?

Although a parastomal hernia may restrict you from doing certain things, you can still live a ‘normal life’. Things like gentle exercise, eating and drinking well, a good stoma product system and a hernia support belt or garment can help you manage your hernia and live a normal life.

Many people who develop a parastomal hernia don’t have any problems or complications. Problems include unpredictable stoma functioning where output alternates between constipation and diarrhoea. The swelling under the skin of the stoma can sometimes cause pain or discomfort. Very rarely the intestines can become trapped in the hernia, this is called strangulation. This can cause extreme pain and can require emergency surgery. Sometimes a hernia can make applying your stoma pouch challenging and can lead to problems such as leakage. It’s important to find a stoma pouch that moulds around your stoma to create a secure seal to help reduce the risk of leaks.

A hernia support belt or garment can help minimise pain as they are designed to support your abdominal muscles, especially during movement, coughing and sneezing. The best way to put on your belt is when you are lying down on your back. Your parastomal hernia will naturally fall back into its original position in the body. When you apply your belt or garment, the parastomal hernia should then be supported by the belt to stay in this position and this will help you feel more comfortable.

Surgical repair

You can ask your surgeon about different options for hernia repair surgery, hernia repair surgery success rates and hernia recurrence rates after surgery. There are risk factors which include general surgical risks such as pain, infection and injury. You might want to consider whether your parastomal hernia is affecting your health and wellbeing enough to consider another operation.

And finally…

If you're concerned about the condition of your parastomal hernia, are experiencing complications, or you think you might have developed a parastomal hernia, please speak to your stoma care nurse – we're here to help!

This piece was written as part of Colostomy UK and SecuriCare's collaborative blog series, 'Stoma Care Nurse Says…'

Keep an eye on Colostomy UK's social media pages for next month's instalment!

For more information see your Parastomal Hernias booklet, available via our website: colostomyuk.org/wp-content/uploads/2019/12/Parastomal-Hernias.pdf

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RACHEL REED:

Never too young

WRITTEN BY JILLIAN MATTHEW

> "When they told me the extent of what they did it was horrendous. I could not get it into my head. I wanted to cry but I was in so much pain."

Rachel Reed, a public health practitioner, from Pontypridd in South Wales was diagnosed with bowel cancer in 2018. Not something she expected, especially at her age – just 33 – and being fit and healthy. She kept going back to her GP with symptoms and was admitted to hospital several times but told she was too young to have cancer, and advised not to worry, it wouldn't be anything serious. This went on for 18 months and unfortunately by the time Rachel got her diagnosis the cancer had spread. Now she is passionate about raising awareness so others don't have to go through the same struggles that she did.

Looking back, Rachel said she wishes she had been more persistent when her GP put her symptoms down to IBS, but she trusted the health professionals. Rachel had been feeling really tired, having abdominal pain and burning and painful cramping in her stomach after eating some foods. When this worsened, she was admitted to hospital and following scans told she had an ovarian cyst, but nothing else was found at that point. Rachel had also been taking medication for chronic psoriasis and thought that this might be causing some of her symptoms. However, her dermatologist said it wouldn't and referred her for a colonoscopy as he was concerned when he learned about the bowel problems she was having. It was only then that it was picked up she had bowel cancer.

Rachel thinks that GPs don't always have time to spend talking through potential symptoms. Her dermatologist had more time to spend with her and picked up there was something potentially serious going on. Rachel highlights the importance of keeping a note of your symptoms to take to appointments and recommends using the symptoms diary on Bowel Cancer UK's website. During her visits to hospital for treatment, Rachel took every opportunity to educate health professionals, such as junior doctors, who she said had a low awareness about bowel cancer in young people. Rachel has set up an Instagram account to increase understanding. Rachel's advice is:

"Always trust what your body is telling you and always keep going back to health professionals if things are not improving."

"I hope readers will be made aware cancer can occur at any age and make sure all your family and friends know if they experience any changes in their body they need to get checked out."

Rachel put into practice her advice of acting on a gut feeling when something didn't seem right towards the end of her chemotherapy treatment. Her blood tests had shown a marker for clots was high and she asked for a scan before she was discharged. She said *"I just knew something didn't sit right."* Although it was not routine to have a scan at that stage, the hospital agreed she could have one and it showed the cancer had spread to one of her lungs. She was so glad she'd asked for the scan, otherwise it would have been another six months for a scan as part of her follow up. The tumour in her lung was successfully removed and following further chemotherapy Rachel had a clear scan showing no sign of cancer in her body in September 2020.

Rachel has had a lot to deal with over the last 3-4 years and said it has been tough. During her surgery to remove the cancer, surgeons found it had also spread to her womb, so this had to be removed as well as two sections of the bowel and a stoma (colostomy) was created. Rachel had given permission to remove all of the cancer but didn't know that she would end up having a hysterectomy. Rachel was offered fertility treatment beforehand but said it wasn't something she could think about. She was more focused on treating the cancer and staying alive but she wishes she was given more advice.

"When they told me the extent of what they did it was horrendous. I could not get it into my head. I wanted to cry but I was in so much pain.

It was in my mind to have children – I was putting my career first though. I was 33 when I was diagnosed and I thought in the next year I will look into having children – I will never have that option now."

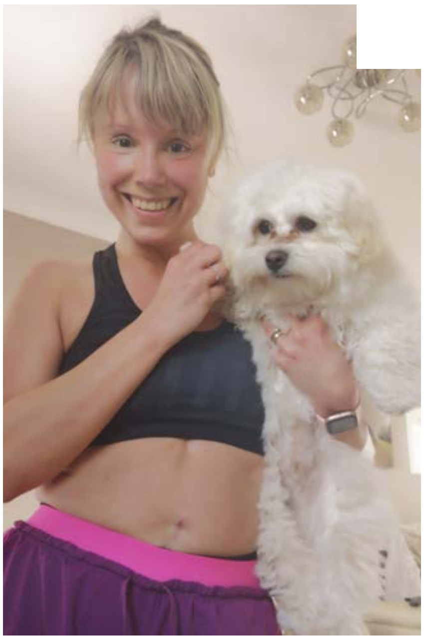
Rachel has a stepson Jac, 17, and five nieces and nephews, and said they all gave her a reason to smile and laugh again. She hopes in the future she and husband Dean will be able to adopt but has been focusing on getting the all clear first. She said someone looking to be an adoptive parent who has had cancer would need to pass initial medical screening and Rachel is concerned she could put a child through further trauma if she had a recurrence.

Rachel has found different ways of coping with her situation and was keen to pass on her tips. One of the biggest challenges Rachel found was how it affected her mental health and immediately after her diagnosis Rachel sought out counselling. She said she received excellent support from a local cancer centre, Rowan Tree Cancer Care in Mountain

Ash, as well as Maggie's Centre in Cardiff. Rachel found there were limited services living in a rural area, especially for younger cancer patients, and gained support via online support groups for people her age. Rachel found the following particularly helpful:

- Trekstock young adult cancer support (20s, 30s) – online support groups, free access to Headspace with guided meditations to help you sleep and exercise sessions.
- Shine cancer support for people in 20s, 30s, 40s – online support groups and events.
- Kicking off against cancer – gave Rachel and her husband a night out to see Jack Whitehall.
- MacMillian Cancer Support – Welfare/Financial support and free support line 0808 8080000 (7 days a week 8am-8pm).
- The Cancer Survivors Companion book by Dr Frances Goodhart and Lucy Atkins.
- You, me and the big C podcast on BBC Sounds.
- Maggies Centres – range of support groups and workshops such as Look Good Feel Better, Yoga, Art Therapy, Life after cancer courses.
- Online free workouts fromBody Coach TV via YouTube and Instagram workouts with Lauren Green @ empowered women fitness.
- Colostomy UK private Facebook support group.

Exercise has been really important for Rachel: *"Exercise is not as easy as it used to be but it really helps with my mental health and helps with my recovery from surgery."* Rachel has combined getting her fitness back with raising money for cancer charities and raising awareness, which gave her a boost. She also joined a weekly choir which lifted her mood. Support from family and friends has made a big difference to Rachel, she said she couldn't have got through everything without them. *"I like to spend my time with my husband, we go out for walks in the local country side and visits to our caravan in West Wales and spend time with our family."* Rachel got a puppy, Sheldon, in March who has brought her a lot of happiness and she wishes she'd got him earlier, recognising the benefits of pet therapy when going through a difficult situation.



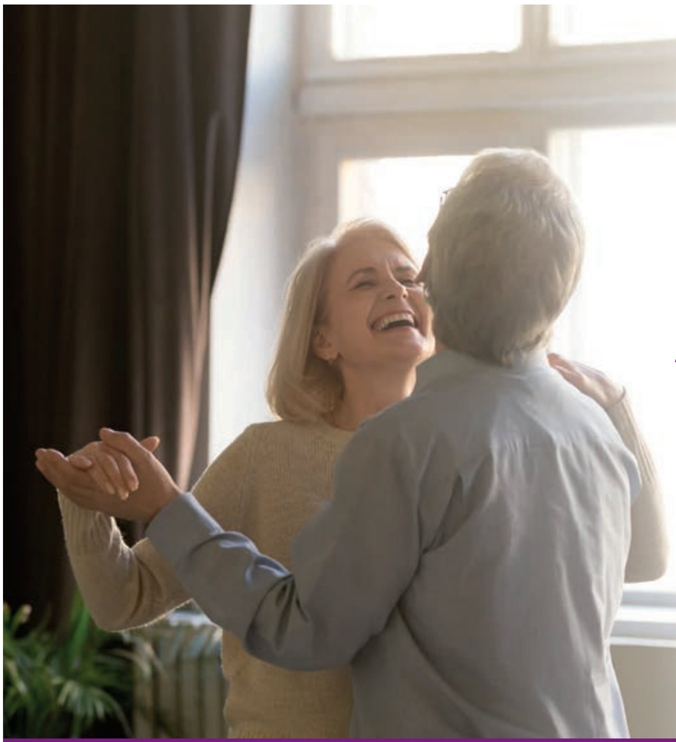
Although Rachel had the fantastic news in March 2021 she was cancer free, there are still challenges. She recently had a stoma reversal, which is currently causing her a lot of problems, and will have ongoing follow-ups for ten years.

Rachel had her colostomy reversed in February, but is having difficulties with digestion months later, possibly caused by adhesions from all her surgery. She hopes things will eventually settle down and wasn't warned prior to the reversal that she could have so many problems, but thinks she may have still gone ahead and wouldn't know until she tried. She still has access to her stoma nurse, has asked for a dietitian referral, and is due to have further investigations by the consultant to find out why she's having so many issues. Rachel said she felt a lot better with a colostomy, could eat what she wanted, but now has to eat *"white stodge"*, otherwise she gets stomach pains, cramps and nausea which can last for hours. Rachel likes to eat healthy food, *"a rainbow plate"*, and worries about the affect this will have on her ongoing health and prevention of cancer and other disease generally.

Rachel said about her stoma: *"It took 3-6 months to adjust to, once I found the stoma products to suit me things got a lot better, switching to a convex bag was a game changer for me along with using stoma protective rings. Keeping in close contact with your stoma nurse is a must in the early days as they have so many stoma products and different bags to make life easier. It was trial and error to find a bag to suit me but once I did the stoma was much easier to adjust to. Sometimes I forgot it was there! The early days with a stoma is tough but you will get there. I had chemotherapy to deal with too and again linking in with my local chemo line to help with side effects is vital."*

Despite ongoing health problems and worries about recurrence, Rachel remains positive and is determined to get through whatever happens next, and continues to raise awareness whenever she can. Given her cancer spread before, she said knowing when to get things checked plays on your mind. The longer it's clear, she's hoping she'll become more confident it won't return. Rachel is extremely grateful to her healthcare team at The Royal Glamorgan hospital and hopes that sharing her story will help others and save a life.

You can find Rachel on Instagram @RachyReedy



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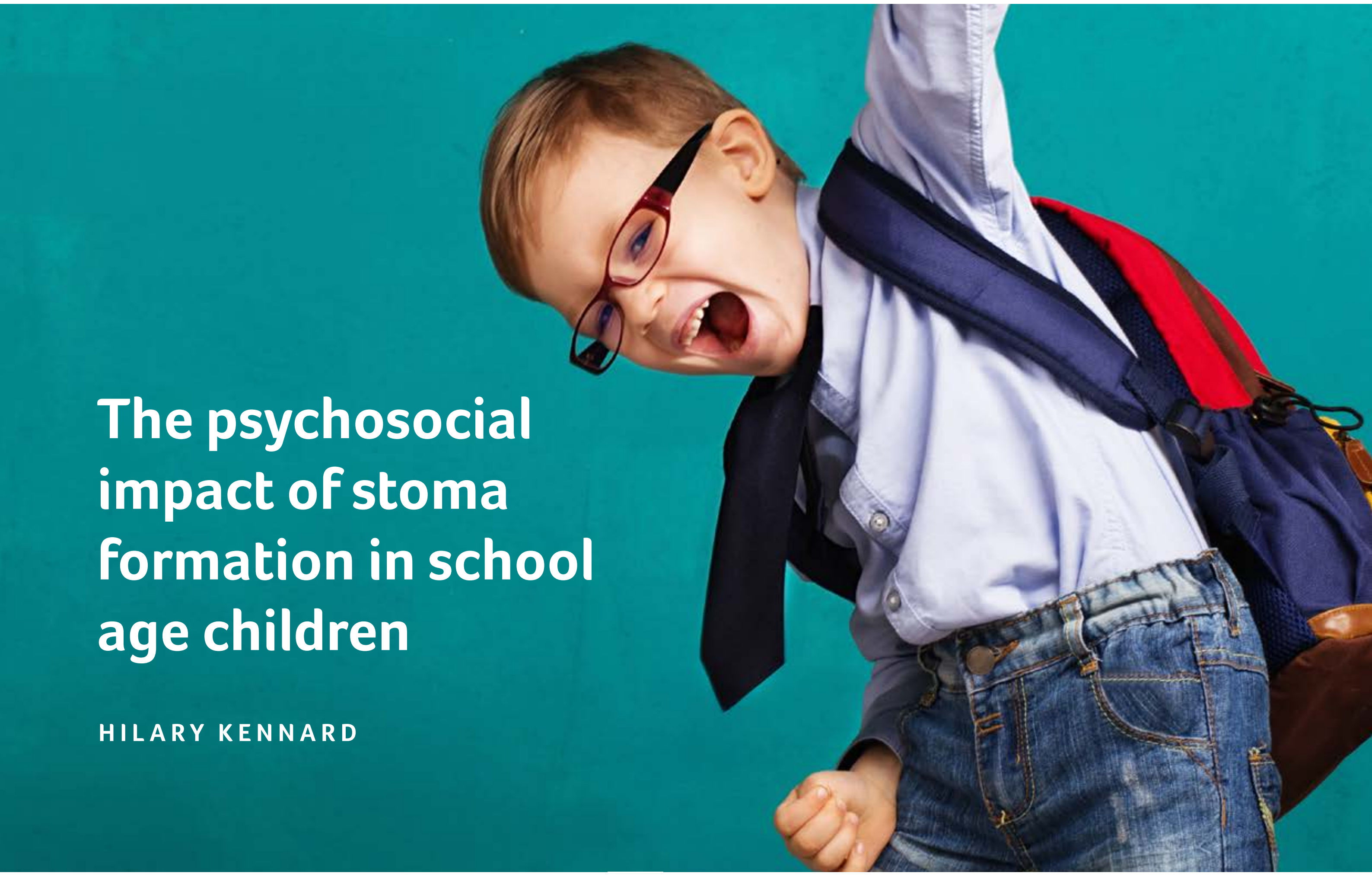

The psychosocial impact of stoma formation in school age children

HILARY KENNARD

Hilary Kennard
Clinical Nurse Specialist Paediatric Stoma and Bowel Management, Bristol Royal Hospital for Children.

The psychological and social impact of living with an ostomy as an adult is a subject that has been studied and reflected on a great deal, but the same cannot be said for children. Indeed, there is little evidence/research for this patient group. This of course has implications for supporting both the children themselves and their families, pre and post operatively.

A small group of healthcare professionals including surgeons, stoma and bowel management clinical nurse specialists, psychologists and gastroenterologists have started the process of correcting this. They have spent the last six years carrying out research to investigate the psychological, social and practical issues children with stomas face.

I joined the group a few years ago. We believe this is the largest qualitative study of its kind ever conducted. One of our key objectives has been to compare the perceptions held by healthcare professionals of the issues school-age children with stomas face with the real, 'lived' experience.

Nine children participated in the initial study (six boys and three girls), with a range of underlying diagnoses. All were under the care of the same surgical team from the same centre. The youngest child was 11 and the oldest 17, with a mean age of 14. All had intestinal stomas or stomas that had been reversed within two years of data collection. The stomas were formed for varying reasons: some as an emergency, some planned. Ten parents took part (seven mothers and three fathers), while members of the surgical team who participated included four consultants and six junior house officers.

The patient and the parent/carer were asked to complete separate questionnaires. The questionnaire was split into six sections: the child's knowledge of their medical condition; reason for their stoma; management of their stoma; how it impacted on their schooling; their sport and social activities; their thoughts on their own body image; their emotional status. The children who took part were also asked to list the three worst aspects of having a stoma and rank them in order of significance to them.

The overriding concern for the children was their bag leaking. One patient said: *"I would not go to friends for sleepovers in case it leaked."* Another said he didn't like playing with more boisterous friends because he feared a leak. A further child commented: *"I didn't get the full information on how much the stoma would leak."* As readers will know, there may be times when the stoma bag leaks. But even knowing this, it remains difficult to prepare a child for this eventuality given that leaks happen more frequently to some than others. Leaks were also a concern for a participant who had never even experienced one. This indicated that fear of a leak is potentially just as debilitating for children as an actual leak itself.

Another concern the children raised was the noise their stoma made. Although the youngest child in the study found this amusing *("I like it when it makes a silly noise because my brothers find it really funny")* for older children it was a source of embarrassment. They were anxious about their stoma making a noise during an exam. In turn, they felt this adversely affected their performance during the exam. One child said: *"I don't eat at school to stop my stoma being active and making noise."* Exams aside, all children felt having a stoma had in some way affected their performance at school and their grades had suffered as a result. Many children reported that they could no longer participate in certain activities, with swimming and gymnastics being particularly affected. They also said their performance in other activities had dropped. This was primarily due to fear of leaks rather than pain or lack of ability. Similarly, most children lacked the confidence to change their bags at school, worrying that it may not stick or may leak afterwards. Leaks and fear of leaks also led to patients having poor attendance records. In this regard, it was also interesting to note that three children admitted using their bag as an excuse to get out of going to school. Absence from school was an area of concern expressed by many parents. Parents also worried about the impact having a stoma would and could have on their child's ability to maintain existing friendships and form new ones. As one parent said: *"I was prepared for the practical issues but not the effect it had on her friendship group."*

The initial study revealed varying levels of support from schools. Some children benefited from access to the disabled toilet or first aid room. One child even reported being allowed to use the headmaster's toilet to empty and change their bag, commenting that: *"It was the cleanest toilet I have ever used"*. However, children also saw a downside to support of this nature, seeing it as something that made them 'feel different' to other students. Support from some schools was found to be minimal. One parent recorded how they: *"would often pick X up from school and he was covered in poo and smelling awful and he had just been left like that all day."*

Despite the negative aspects to having a stoma, some children recorded positive outcomes. These included: not having to take as much medication; not being in pain anymore; not having to wear nappies. One child said they liked having the stoma because: *"I felt better and got back to the things I liked."*

The healthcare professionals who took part in the study were also asked to rank what they thought would be the three main concerns of children. They perceived that body image would be a key concern, especially amongst adolescents, while they thought younger children would be more likely to want to show their bag off to friends. Only one of the healthcare professionals (who incidentally had a family member with a stoma) recognised that there might be an issue for children using public or school toilets. Their responses also highlighted uncertainties around some of the practicalities of living with a stoma as a child, such as going swimming or taking part in contact sports. Comparing the responses of the children and their parents with those of their healthcare team revealed other differences between perception and reality. Despite some of the patients going on to suffer from the complications that were discussed with them and their parents during the pre-operative consent process, these were not listed in the three key issues identified by patients and their parents.

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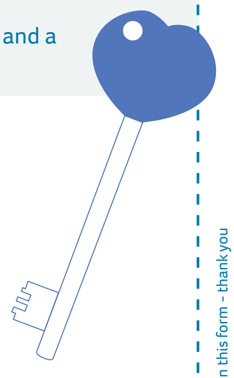

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An important outcome of the study was to highlight the detrimental effects that having a stoma can have on a child's school life and social interactions. This was found to be underestimated by the healthcare teams looking after these children. The children and their families felt that there was also a discrepancy between the positive description of life with a stoma provided by leaflets, videos and websites and the reality of living with one. As a result of this initial research, we are pleased to report that a larger, nationwide study was instigated, involving 26 paediatric surgical centres across the UK and Ireland. The data is currently being analysed. Hopefully this will lead to more realistic pre-operative counselling, with information that is age appropriate and will provide a better way of managing children's (and parents) expectations of what lifewill be like living with a stoma both practically and psychologically.

Your letters and emails

Editor's note: A few editions ago, we published a letter titled 'How Green is Your Bag?'. It seems that this struck a chord with many readers, as Mrs Rice's subsequent letter (last edition), prompted a flurry of comments and suggestions, a selection of which appear here. If you have the time to drop me a line (letter or e–mail) then please do. I have been wondering how people have found coming out of lockdown? Has it presented any particular challenges as an ostomate?

Dear Editor,

I want to reply to the letter from Mrs M Rice in the summer Tidings.

Maybe she would find a drainable pouch more suitable? I have used Dansac drainable pouches for 14 years for my colostomy. They are easy to empty and I usually change the bag once a day or every two days. You can flush them out with warm water while attached to your body if needed.

When I am going out for the day or away I take a Loperamide Hydrochloride tablet the night before to make the poo firmer (like rabbit poo) which is easily disposed of, especially in public toilets. I spray the bag inside with baby oil before attaching to my body. So a bag can be emptied several times before needing a change which all helps the environment.

Sheila and "Bilbo"

Dear Editor,

I have been reading your magazine for a number of years and am always heartened by the accounts of courage and determination shown by fellow ostomates. I do want to say, however, to anyone facing the possibility of having an ostomy: "There may not actually be any problem or limitation". In my own case life simply continued as before with a slightly more complicated method of passing body waste!

I had been very active until having to take early retirement due to heart failure in 1987, followed by two lots of bowel cancer, the second resulting in a stoma in 1996. Since then I have continued to travel extensively: camping holidays all over France; several visits to stay in the (fairly basic) home of a Sri Lankan pastor in Batticoloa; one memorable visit to China with a small group, travelling on local trains, sometimes overnight and queuing in the corridor to use the lavatory. I have never needed to watch my diet and have been able to join walking and swimming activities with fellow travellers, until arthritic knees stopped me.

Honestly the only problems I can remember are the two occasions when I did not pack enough pouches: my wife sent a packet to Sri Lanka and a local hospital provided in Scotland.

I really feel at 90 that my life has not been curtailed by having a stoma. I am very thankful for this and want folk to know that this can be the case and there is no need to be frightened. With all good wishes to you and to the readers of the magazine.

Yours faithfully,

J M, Newcastle upon Tyne

Dear Editor,

I read Mrs Rice's letter in the Summer 2021 Issue with great interest. Like her I am keen to reduce the number of bags I use. I also have a colostomy and although it is not I believe generally recommended I actually use a drainable two–piece bag and have done so for over 20 years. This enables me to empty the contents several times a day via the bottom section of the bag which is easy to undo and redo, and I am able to use the same bag over a period of about a week.

At one time I changed the bag after about a week but continued to use the same flange for a further week. Recently, possibly because of my age, I am 88, I find that the flange needs replacing about every week so I naturally change the bag at the same time. So why, you might well ask do I continue to use the two–piece bag? The answer is that the transparent flange gives me a visible indication of when I need to change it - the one–piece bags do not do this.

I must be one of the worst "colostomites" from the point of view of the producers of colostomy products but I believe in saving the NHS as much as I can. The worst part of having a colostomy from my point of view is having to change the bag and flange but with my system I have reduced this to an absolute minimum. I use Dansac flanges and bags. I hope this might not only be useful to Mrs Rice but to others with a colostomy.

Ken Drake, Cambridge

Dear Editor,

The article about pancaking in issue 62 missed one very effective solution - filter covers. My mum had a persistent problem with pancaking but didn't know about filter covers as they weren't supplied with her pouches.

In your magazine, many years ago, someone asked what they were for and another reader subsequently replied and included the anti-pancaking tip. After trying out with label stickers, I wrote in and asked readers if they could spare any for Mum - the response was amazing and your wonderful readers sent so many that I had to start turning them down. Mum never produced an unwanted pancake again!! When her new delivery of pouches arrived, we fitted a filter cover to each one. In use, the cover would allow a small amount of gas to stay in the pouch, this broke the vacuum and created an 'air cushion', allowing space for the output to enter the pouch fully. If there was too much inflation, Mum would simply remove the cover during her next bathroom visit, attach it close by on the pouch until some gas had dissipated, then apply the cover again, as needed. It's so simple yet saved much stress and embarrassment.

Mum, sadly, died recently but we were both grateful for that article so many years ago and for the kindness of so many of your readers.

Many thanks,

L. W. Hampshire

>>

Dear Editor,

As a colostomist of 18 years I wondered if any readers have had a similar experience or any advice as all of the professionals I have approached have been unable to give me a definitive answer.

Approximately ten years ago I began to have 'bouts of distress' which at first I put down to norovirus. These occur on roughly an annual basis and follow the same pattern:

- Gradually worsening pain in the pit of my stomach.
- Yawning.
- Feeling dreadful and tearful.
- Being violently sick two or three times, or until pain goes, followed by excessive diarrhoea.

These events always start early evening with the sickness occurring in the night.

It has been suggested it could be diet related, however I tend to eat the same foods, plenty of fruit and vegetables. Scar tissue or a change in gut flora, post-op, have also been suggested as the cause.

I look forward to hearing from anyone unfortunate enough to suffer similar.

Sue, Newcastle upon Tyne

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 chequemade payable to Colostomy UK, to:

Colostomy UK, Enterprise house, 95 London Street, Reading, Berkshire, RG1 4QA
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Sophie Brown's rollercoaster life with bowel cancer

WRITTEN BY GILLIAN CASTLE

It's June 2021 and I am at Thorpe Park on the thrill–seeking rides with my son Jacob, aged 12, and my partner, Anthony.

We spend the whole day together, screaming on the rides and feeling the exhilaration of speed on the rollercoasters. My life had been a rollercoaster all of its own, since the summer of 2019, when my whole world was turned upside down. During the intervening two years, I never expected that I would be back at theme parks, or out enjoying life with my family.

In 2018, I was 35 years old, working in the Offender Management Unit at the Prison, where I had been for over seven years, and living an active, happy life with Anthony and Jacob in our home in Surrey. I started experiencing strange symptoms, bleeding out of my bum and always tired. I started losing weight. My pain was intermittent, which meant that I couldn't predict when the pains would shoot through my body. I began cancelling meetups with friends at the last minute, worrying that as my pain was internal, they wouldn't believe that I was feeling poorly.

I went to my GP, who referred me for tests, but I was repeatedly assured that my symptoms were not signs of anything serious. I was told that they were down to everything from irritable bowel syndrome (IBS) to Crohn's disease, and even when I asked whether I could have bowel cancer, I was told that I was too young. I knew that there was something wrong with my body, and I felt like I was losing my mind. I was frustrated and extremely upset that no–one was taking me seriously. My mental health changed dramatically. I had gone from being happy, and active, to anxious and feeling like I was going mad.

By February 2019, the pain had become unbearable, I started vomiting and had to go to A & E. This was the start of a long road, with repeated trips to A & E, where I ended up more than eight times. By April I was diagnosed with pelvic inflammatory disease, which resulted in the removal of my fallopian tubes. During the surgery my bowel was accidentally cut open, and a tumour was discovered. A colonoscopy was booked, and I was told two weeks later that I had localised stage four bowel cancer. The cancer had been there for 18 months by this time.

This was the worse moment. I was devastated. I had done everything I was meant to do. I'd looked after myself and gone to my doctors, but I was repeatedly ignored and now here I was – diagnosed with advanced bowel cancer.

Eight days after the diagnosis, in late July 2019, I was told that I would need an operation to fit a stoma. I knew what a stoma was, as when I had first started feeling poorly, I had researched what they were. Even though I was being told I had either Crohn's disease or IBS, in my gut I knew it was bowel cancer and a stoma would be a likely outcome if I was right. However, I didn't know anything about the bags that were used, or the practicalities of having a bag fitted. The first thing I said was: "What? I've got to poo out of my stomach? That's disgusting." I couldn't get my head around it at all, and I couldn't understand how I could go to the toilet in this new way.

When I woke up, I was under the care of two stoma care nurses, who worked really hard to help me with my new colostomy. Less than five hours after my surgery, I was left to manage changing my bags myself, which I felt unable to do. I couldn't even bear to look at my stoma for the first week, I felt it was like a foreign body on my stomach. In my mind, I knew that I could change the bag, but when it came to actually doing it myself, I couldn't. I needed more time to adjust to the big change.

When I came out of hospital, I had a lot of support from my family and friends. They were all very encouraging, telling me that I could manage, but sometimes I felt like they didn't understand how much my life had changed, and how much I was struggling. I saw the stoma care nurse weekly, but soon after I came home they told me that they wouldn't be able to see me at home as often,but that I could book to see them at the stoma clinic. I didn't feel ready to manage my stoma on my own, and so I reached out to people on social media.

My son, Jacob, has made me really proud with how he has coped with my illness, and my bags. I was very honest with him from the start, and although he didn't like the idea of my bag initially, he has become fascinated with the digestive system. He even took a stoma bag into school to educate his friends, who think it's cool that I don't have to run to the toilet. Jacob is happy I have bags as he sees them as a sign that I am getting better. He is always looking out for me, making sure I have my spare bags with me when we go out. Anthony has also been fantastic and, by some weird coincidence, his previous girlfriend also had a stoma. Jacob and Anthony have helped me to accept my bags,we are a strong family unit.

I had some problems with my stoma, particularly with blistering on my skin, but I was given barrier powder to use which helped. I am also waiting for samples to arrive of barrier spray to see if that can also help. Even though I did have some issues with bag leaks, I didn't let it stop me from doing anything.

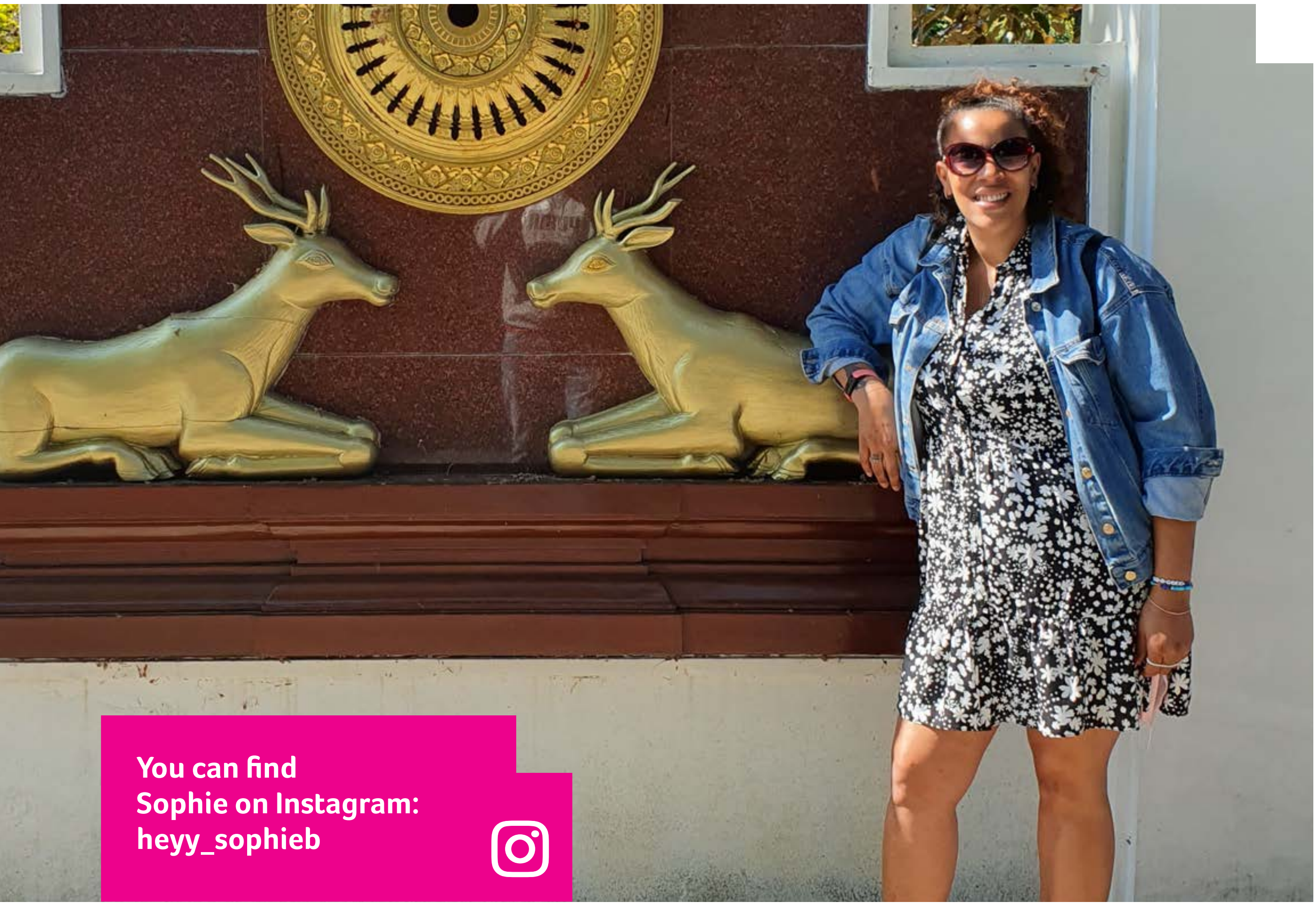
On 22 March 2020, one day before the first national lockdown, I underwent total pelvic exenteration surgery which resulted in two stomas: a urostomy and a colostomy. This was deemed necessary because my tumour was literally sitting on top of my bladder, and some nasty looking things were found in my

cervix. The surgery was about both treatment and cure. The surgeon wasn't sure what he would find when he opened me up, so I asked my mum to signal with her fingers when I woke up – one finger would mean I had one bag, and two fingers would mean I had two bags. When I saw her hold up two fingers, I felt tears running down my face. I was incredibly upset about the urostomy as it was another stoma to get used to.

In the last year I have accepted my bags and embraced them for the life that they have given me, although I do struggle with more mixed emotions over my urostomy. I know that these bags are always going to be with me, and so I have opted to get on with life as best I can. In fact, lots of good things have come out of me having my bags. I have made some incredible friendships, both virtually through online support groups, and in person. Having my cancer has given me balls. It has made me feel honoured, lucky and brave. If I didn't have the operations to create the stomas then I would be dead, and not everyone gets the opportunity to undergo such complicated surgery.

I have also been involved in the Bowel Cancer UK "Never Too Young" campaign, which is leading the change for younger bowel cancer patients. My own diagnosis came late because bowel cancer was not considered as a possible cause until over a year had passed, due to my relatively young age. According to Bowel Cancer UK, every year over 2,500 younger people are diagnosed with bowel cancer in the UK. It is very important to me to help raise awareness that it is possible to have bowel cancer at a young age, as it might help someone get a diagnosis and treatment quicker than I did.

I would say to anyone facing stoma surgery that you're going to have good and bad days, which is normal, but you will get through them all. It is ok not to be ok. Try different bags out. You don't have to use the ones first given to you by your stoma care nurse, you are free to experiment and request samples of other kinds of bags. Bear in mind that no question is too silly, it's all very new and you will have lots of questions about everything. With time you will be able to get back to doing all the things you did before you had a stoma. I have even passed my driving test since getting mine and been on theme park rides!



You can find Sophie on Instagram: heyy_sophieb

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 e–mail: **info@ColostomyUK.org.**

Wessex Stoma Support Group

Ken Edwards, Chairman writes: A limited number of members were able to meet and hold the AGM back in June. Thanks to the Covid-19 regulations, this was the first time in our history that it has been conducted in the open air!

During the pandemic we made use of Zoom to meet, hold committee meetings, and work with national organisations. We are now looking forward to gradually 'opening up' again. From July onwards (regulations permitting) we re-start our programme of meetings and events. This includes the annual BBQ, our 15th Birthday celebration and a day at the seaside. We also have our Christmas dinner arranged, along with a trip to pantomime (both of which we had to cancel last year).

Wessex Stoma Support Group meet at: Bob Blandford Memorial Scout Hall, Wilton, Wiltshire. Contact Karen Berryman.

T: **01980 590 599**
E: **info@wessex-stoma.co.uk**
W: **www.wessex-stoma.co.uk**

Second Chance Ostomy Support Group

Second Chance Ostomy would like to invite you to their very first stoma support group to be held at the Community House in Selby, Yorkshire on Friday the 3rd of September.

We look forward to welcoming you and your family/friends. There will be a free raffle and refreshments available.

We will be holding one session in the morning at 10:00 and one in the afternoon at 14:00.

Please call Jackie at Community House on **01757 261 111** or **jackie@secondchanceostomyyorkshire.org** to book a place.

Please note the venue is a Covid secure area and current government guidelines must be adhered to.

Open Days

Shropshire B.O.T.S. (Bums on Tums) 2021 stoma open day:

Thursday 7th October 2021 10:30 – 15:00.

Location: The Memorial Hall, Smithfield Street, Oswestry, SY11 2EG

12 Suppliers and Distributors will be exhibiting and promoting their products, including any new items and offering complimentary samples. Complimentary light refreshments will be provided and there will also be a raffle.

Contact: Irene Constable on **01691 238 357** or email **ireneconstable@phonecoop.coop**

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
E: wamsstoma@gmail.com
T: 0118 939 1537

Bristol

Bristol Ostomy Self Support (BOSS)
Janet T: 01934 248 114
Rob T: 0117 966 8021

Buckinghamshire

High Wycombe Stoma Support Group
T: 0800 318965
Milton Keynes Stoma Support Group (MKSSG)
Morag Harvey (Secretary)
E: mkssg.sec@gmail.com
T: 07843 768 386
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 / 07836 661 102 | W: ostomistics.org

Cheshire

Countess of Chester Hospital Stoma Support Group
Stoma Nurses T: 01244 366 170
Stockport Support Group
Marion Caulfield
T: 0161 320 9400 / 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: 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

Diverted Local Stoma Support Group
Diana Manning T: 01283 541 311
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: janice234ford@gmail.com
T: 07923 975 051
Plymouth & District Bowel Cancer Support Group
Rita T: 07855 571 840
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
Lin Hart T: 01279 505 273
E: comeconnectwithus@gmail.com
Mid Essex Stoma Support Group
Paul Foulger T: 01245 224 374
N.E.S.S (North Essex Stoma Support)
Brian Waller T: 01206 540 449
Optimistic Ostomates
Angela Taylor T: 01702 385 510
Redbridge Ostomists Club
Stoma Nurses - Chris / Lisa
T: 020 8970 8321
STEPS - Stoma Essex Patients Support
T: 01268 451 937
E: stepsessex@gmail.com

Hampshire

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 Man

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

Isle of Wight

Optimistics
CNSs Sarah Capon & Sarah Varma
T: 01983 534 009

Kent

Ashford Stoma Support Group
Carol Hobbs T: 01303 814 014
Treasurer, David Christian
T: 07970 220 773
Secretary, Maureen Curnow
T: 07989 773 332

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
or Helen T: 07710 780 958

MOGS (Medway Ostomy Group Support)
Tracey T: 07779 155 846;
Helen T: 07710 780 958 or
E: mogs-uk@hotmail.co.uk

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

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

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

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

Oldham Stoma Support
June Wilde T: 0161 312 5538

Phoenix Bowel Cancer Support Group
Sandra Peet T: 01772 683 790
W: phoenixgroupbvh.com
E: sandrapeet7@aol.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
Angela Davy T: 020 8510 5318
or 020 8510 7599

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 or 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
Denys Floyd T: 01744 884 097

Middlesex

Inside Out
Sarah Varma T: 020 8235 4110
Bob (Chairman) T: 020 8428 4242

Norfolk

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

Kings Lynn Ostomy Friendship Support Group
T: 01553 775 698, 01553 674 962, 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
Judith T: 07967 927 286

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
Rosemary Brierley T: 0115 982 6691

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
Marion Fisher T: 01473 311 204

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

Normandy Colostomy Support Group
Robin Young
E: robin.young11@btinternet.com
T: 01483 417 610
W: normandystomagroup.wordpress.com

Stoma Support Group
Robin Young T: 01428 723 255

Sussex

Brighton & District Support after Stomas (SAS)
Virginia Keefe T: 01273 723 775
Chichester Stoma support Group
The Stoma Care Team
T: 01243 831 527
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
NHS Molineux Support Group
John Burchell T: 0191 265 1047
Royal Victoria Infirmary Support Group
Stoma care nurse specialist
T: 0191 282 4116
Sunderland Support Group
Michele Downey T: 07704 949 30
E: micheledowney@outlook.com

Warwickshire

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

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

Wiltshire

Swindon IA
W: swindon-ia.org.uk
Wessex Stoma Support Group
Karen Barryman T: 01980 590 599
or 07799 863 766
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 or
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 E: Secondchance-ostomyyorkshire@gmail.com
T: 07544 882 353
W: secondchance-ostomyyorkshire.org
The Hull and East Riding Colostomy Support Group
Pete Smith T: 07989 565 335 or
Pete Rennard T: 07939 518 642 /
01482 793 966 W: hercosg.org.uk

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) National
Cancer Helpline T: +353 1 800 200 700 or
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 or
Rhona T: 01294 557 478

Fife

Fife Ostomy Support Group
Ishbel Barr T: 01592 772 200

Lanarkshire

Glasgow Stoma Support Group
Morag Sinclair T: 0141 779 1322 or
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
Nancy Fraser E: nancyfraser@talktalk.net
T: 01450 374 012
Fiona Gentleman E: r.gentleman@sky.com
T: 01450 371 063

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 or
Julian Boswell T: 01554 772 877

Conwy

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

Gwent

Blaenau Gwent Self Help
Celia McKelvie T: 01873 852 672 (after 6pm)

Cwmbran Ostomy Support Group (COSG)
Philippa Lewis T: 01633 791 339 /
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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