Spring 2021 | Issue 61

Supporting and empowering ostomates

Colostomy UK's Award Winning

Tidings

From baby, to bag and beyond – Triathlete Gillian Castle talks about life after birth trauma

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Dear readers

Front cover:

Gillian Castle

'Caring for a Person with a Stoma' workshops delivered by Stoma Care Nurse, Joan Garwood

It's normally around this time of year that I get a burst of energy. With those dark, wet mornings and gloomy afternoons receding and the first hints of spring in the air, so my spirits are lifted. It signals the approaching end to winter's nocturnal existence; no more going to and from work in the dark! Instead, it's time to break the hibernation and get out and about. It's the moment to start thinking about booking a summer holiday. I even have some enthusiasm for doing jobs around the house. This year is, of course, very different. As I write this all those signs of spring are here, just not my usual verve and excitement.

2020 was a tough year and I think it's vital we admit this. I doubt anyone has come out of it unscathed. But, to my mind, reflecting on the last 12 months and thinking about all we have been through, is the best way of staying strong and moving forward. Covid–19 is the UK's 21st Century Blitz, and just like the last one – we will prevail! Hopefully this edition of *Tidings* will help give your mood a well–earned boost. So get the kettle on, put your feet up and escape the madness for a few moments!

As usual we have all the regular features. In particular, I would like to draw your attention to the item in **Colostomy UK** news about Covid–19 vaccines. If you have been concerned about their safety in relation to people with stomas, then hopefully you will find our statement on the matter reassuring. In Dear nurse our very own Ambra Bertinara deals with the issue of blockages and gives plenty of useful advice for people with both colostomies and ileostomies. Jennie Burch tackles another common problem: rectal discharge. She explains why a retained rectal stump can lead to this and suggests a number of ways to manage it. We have two further articles which I hope will be of interest. On page 20 you can read about some stoma awareness training we have recently delivered. The importance of doing this type of work cannot be underestimated. On page 18 you will find the preliminary findings of some research conducted by a Masters' student at Manchester Metropolitan University, around perceptions of body image amongst sufferers of IBD. We were pleased to support this work and are very grateful to members of our private Facebook group who agreed to take part.

We have six Real Lives stories for you to enjoy. We catch up with Jessica Logan whose story we covered last spring. Gill Castle picks up on a topic we covered last edition, recounting how a childbirth trauma led to her having a permanent colostomy. As you will see she has gone from struggling with what happened to embracing life again. Similar can be said of Lizzie Whitchurch, another truly inspirational woman who hasn't let years of suffering chronic illness dent her optimism and love of life. Ken Edwards' story recounts a very varied past, including spells as a singer and time in local politics. Since his stoma surgery Ken has been campaigning in his area for stoma–friendly facilities as well as working hard to develop local support for ostomates. Our final two stories are a little off–piste… Rachel Dodman explains what it is like living on a narrow boat when one of the family on board has a stoma, while John Hunter has submitted a collection of poems which capture key moments in the life of an ostomate.

Happy reading!

Richard Biddle
Editor,
Writer &
Researcher


freedom to be...
...transported to another world
Norman, 67
Aura

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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*
0118 939 1537

info@ColostomyUK.org

Editorial Enquiries
Letters, articles or other submissions

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info@ColostomyUK.org

Advertising enquiries
For a media pack and advertising rates: **0118 918 0500**

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!

Donating to Colostomy UK

An annual donation of £25 (or whatever you can afford) allows us to produce *Tidings* and to continue our vital work, supporting, and empowering ostomates – see page 41 for donation form.

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

Colostomy UK

Annual Prize Draw

gives **you** the chance to **win**

£2,500!

Tickets are only £1 each and all money raised from the draw will go towards supporting vital Colostomy UK services such as our 24–hour stoma helpline, support literature and Tidings magazine. A book of 10 raffle tickets is enclosed – if you would like to purchase more please get in touch by calling 0118 939 1537 or e–mail info@Colostomyuk.org. Simply fill in your details on the tear–off slip and post this section back to us along with your payment. **Every ticket purchased helps us to support and empower ostomates.**

Colostomy UK: news

Libby Herbert
General Manager
E: libby.herbert@ColostomyUK.org

New Joiner - HR trustee Preeti Johal

Preeti joins Colostomy UK as our Human Resources (HR) Trustee, bringing with her over 20 years of experience in the field gained working in the charity and healthcare sectors as well as in local government and public services. Looking back over her career, Preeti says she more or less 'fell' into HR while at university; it was here that the seeds for what she terms her 'HR passion' germinated. She is now Chartered Institute of Personnel and Development (MCIPD) qualified and also delivers training in various aspects of HR practice.

Her first professional engagement with the charity sector was seven years ago and she hasn't looked back since. Being able to make a difference supporting charities with her expertise is something that gives her a great deal of job satisfaction! Preeti first became aware of Colostomy UK two years ago, shortly after her twin sister was diagnosed with bowel cancer. Both Preeti and her sister found Colostomy UK to be a great source of support and information. She was also attracted to our mission and values.

Preeti, who lives in west London with her partner, tries to live a plant–based life and has a love for animals and football. She is also a firm believer in doing everything you can to have a healthy body and healthy mind and so takes part in all sorts of activities, including: yoga, weight training, running and football.

She is really excited about joining Colostomy UK's board of trustees and is particularly grateful that she can use her expertise for an amazing cause.

Caring for a person with a stoma workshops delivered virtually

Colostomy UK has been delivering 'caring for a person with a stoma' workshops in the community since 2015. When the pandemic hit, we feared that these vital workshops would not be able to go ahead, but we are delighted to share that we will now be delivering these training sessions online thanks to support from the Ernest Hecht Charitable Foundation.

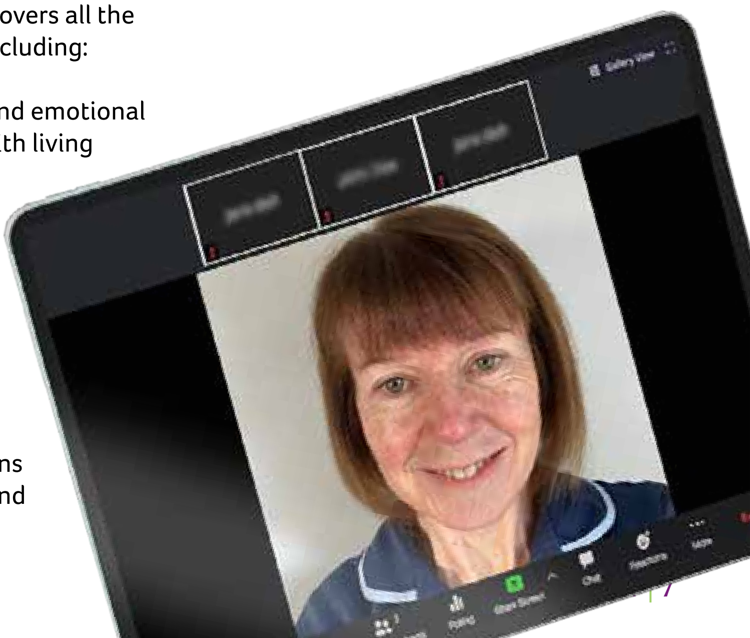
These workshops are aimed at professional carers and family members as well as anyone responsible for supporting someone with a stoma.

They provide attendees with practical advice and guidance on how to care for someone with a stoma. Each 90–minute session, which is delivered by a stoma care nurse, covers all the need–to–know topics including:

- the psychological and emotional issues connected with living with a stoma,
- practical stoma management,
- a guide to different appliances,
- common concerns,
- dementia.

Two initial virtual sessions took place in February and early March.

If you'd like to join a future workshop please get in touch with us at info@colostomyuk.org or by calling 0118 939 1537



Colostomy UK: news

In partnership with AccessAble

In a world where face–to–face meetings are on hold, technology has become a critical tool in our arsenal, allowing us to continue in our mission of raising awareness and advocating for ostomates. Our partnership work has not stopped, in fact we have formed additional partnerships, and we continue to deliver training to organisations virtually, to inform and upskill their employees, creating a more 'stoma aware' society and ultimately improving the experience of ostomates.

We have partnered with AccessAble as part of our Stoma–Friendly Toilets campaign. They produce an accessibility guide, with detailed information about venues all over the country. Since we announced our partnership on Thursday 3rd December (International Day of People with Disabilities 2020), every toilet that they have surveyed has been checked to see if it has 'stoma–friendly' facilities. If a toilet does not meet our criteria, then AccessAble's surveyors will work with the organisation to make the necessary changes. Stoma–friendly toilets will be listed as such in the guide and they will be searchable on the AccessAble website and app, so that ostomates can see which shops, pubs, restaurants, cinemas, theatres, railway stations, hotels, colleges, universities, hospitals and more have stoma–friendly toilets! Over time as more toilets are surveyed, more toilets will be added to the guide.

> "With AccessAble on board there is a huge opportunity to increase the number of stoma–friendly toilets across the UK"

In order for a toilet to be classified as 'stoma–friendly' it must meet the following criteria:

- Hook on door. To hang clothing, handbags and luggage while changing stoma bags. This provides more space in the cubicle.
- Shelf space. To enable ostomates to spread out their items easily and avoid having to use unsanitary surfaces.
- Accessible toilet signage. To highlight the right of ostomates to use the toilet. Reduces risk of hostility when using an accessible toilet.
- Mirror. To enable users to see their stoma while changing their bag.
- Disposal bin in every cubicle. To avoid embarrassment for men and women having to dispose of their stoma bag in public view.

Gregory Burke, Founder of AccessAble, said of the initiative:
"From the moment we met the team at Colostomy UK we could see how working together could make a really big difference to people living with a stoma. We want to end toilet anxiety, to truly take the chance out of going out, so that no one faces uncertainty about using a toilet outside of their home. As part of this commitment, we are really delighted to launch the Stoma–Friendly Toilet symbol on to the AccessAble website and App. We also look forward to promoting the importance of Stoma–Friendly Toilets and helping to increase the number available."

Speaking about the partnership Libby Herbert, General Manager at Colostomy UK said:
"We are delighted to be partnering with AccessAble to ensure that more toilets across the UK are Stoma Friendly. It has been great to work with and train the AccessAble team of surveyors on what makes a stoma–friendly toilet. With AccessAble on board there is a huge opportunity to increase the number of stoma–friendly toilets across the UK and raise awareness with organisations about the needs people living with a stoma have."

To view the AccessAble Guide, visit: accessable.co.uk/ To find out more about our Stoma–Friendly Toilets campaign visit: colostomyuk.org/campaigns/toilets/

AccessAble
Your Accessibility Guide

The UK Civil Aviation Authority Airport Accessibility Report

Colostomy UK is proud to be actively working with a number of airports across the UK to train and support them (virtually) in meeting the needs of travellers with a stoma and other hidden conditions.

To monitor airports' accessibility, the Civil Aviation Authority produce an accessibility report each year. We have been supporting Birmingham, Bournemouth, Cardiff, Edinburgh, Gatwick, Heathrow, London Luton, London Stansted, and Manchester airports. For the first time, no airports were ranked as poor in terms of accessibility and we are delighted to share that all airports have been ranked as "good" or "very good" in the UK Civil Aviation Authority's 'Airports Accessibility Report 2019/2020'. This is an excellent step forward for disabled and less mobile passengers.

To read the full report, visit: http://publicapps.caa.co.uk/docs/33/CAP%201978.pdf

Launching 'GOAL'

We were excited to launch our new Giving Ostomates Active Lifestyles (GOAL) project on 1 March. GOAL is an eight–week pilot programme designed to support people with stomas get back into healthy eating and exercise. The pilot is focusing on ostomates in the north east of England.

We are delighted to be working with Jo Prance, Personal Trainer and Sophie Medlin, Consultant Dietitian (with expertise in gastrointestinal and colorectal health). The sessions run twice weekly on Zoom. Jo uses her session to focus on exercise while Sophie uses hers for a structured group discussion on dietary intervention. The aim of these sessions is to support participants in making small steps towards better health.

The aims of the project include:

- increased uptake of exercise;
- increased confidence with physical activity;
- increased intake of fruit and vegetables;
- reduction in the consumption of processed foods.

This project has only been made possible thanks to money from the legacy of Isabel and Derek Jonas which was gifted to us to help us increase the support we offer to the ostomate community in the north east. As we are a self–funding charity, donations such as legacy gifts are vital to allow us to continue supporting ostomates. Many people are put off leaving a gift in their will, as they think they need to give a substantial amount. This isn't the case. Every penny left to us is put to good use helping ostomates of today and tomorrow. If you leave us a gift, we will use it where we feel the need is greatest. Alternatively, you can request that you would like it to help ostomates in a particular part of the country.

We hope that GOAL will have positive outcomes for the individuals involved. If this pilot is successful, we hope to launch further interventions later in the year. Keep an eye out in future issues of Tidings, our website, and social media (Facebook, Instagram and Twitter) accounts

Find out more here: colostomyuk.org/active-ostomates/goal-giving-ostomates-active-lifestyles/

Is the Covid–19 Vaccine Safe for Ostomates?

The rapid development and roll out of the Covid–19 vaccine seems to be the topic on everyone's lips at the moment, and we have received questions regarding its safety for ostomates.

Ian Daniels, Colostomy UK's president had this to say:

"On the whole we recommend vaccination against Covid–19. There is no evidence that ostomates are at any increased risk of side–effects from the vaccines currently licensed. Specific guidance for those with inflammatory bowel disease and those receiving chemotherapy has been issued but we recommend that you discuss this with your GP, Specialist Nurse or Consultant if you have specific concerns. Ostomates who are pregnant will need to see specialist advice about the vaccine types"

For further information visit the British Society of Gastroenterology: https://www.bsg.org.uk/covid-19-advice/british-society-of-gastroenterology-inflammatory-bowel-disease-section-and-ibd-clinical-research-group-position-statement-on-sars-cov2-vaccination/n

Colostomy UK: news

Metropolitan Police (MET)

On Thursday 3 December, Colostomy UK General Manager, Libby Herbert, attended the Metropolitan Police Service's Disability Staff Association 'Day of Disabilities' virtual event on hidden disabilities and conditions.

With 130 members of the police service in attendance, Libby was invited as a guest to join an internal panel who discussed a range of hidden health conditions and disabilities including endometriosis, dyslexia, fibromyalgia – and, of course, stomas. As part of the event Libby held a question–and–answer session and Colostomy UK Ambassador and police officer Nav Johal (pictured) shared her story. Nav was diagnosed with bowel cancer in February 2019 and now has an ileostomy. She addressed her colleagues about living with a stoma, eloquently and clearly explaining the practical needs of ostomates working for the MET as well as the emotional impact of the surgery.

Talking about the virtual event, Libby said: "I was honoured to be invited as a guest to the Met police's International Day of Disabilities event to hear Nav share her journey with cancer and life with a stoma. It's not an easy task to do but she was brilliant, and I was pleased to be able to support her, answering her colleague's questions and raising awareness of the needs of ostomates."

Together Libby and Nav shared the importance of having stoma–friendly toilets, and the changes that the MET could employ to support ostomates.

Nav is now in remission from cancer, awaiting a reversal, and she has returned to work: "Importantly for me I have been able to get back to work full time during lockdown. This is something that has worried me, having a stoma and working. Looking on social media I have seen other ostomates that are in the blue light services, this made me think why should a stoma stop me from being a police officer? Obviously, life can't be exactly the way it was for me but with some adjustments and protection, with the right support I know I can still do my job. With my disability I can sometimes have days when I don't feel great, it's important to use your colleagues, support groups and your family and friends. You need people to hold you back when you push too far, whether it's at work, exercise, activities, or just general life. You don't need to stop completely, but pause and take a breather, maybe make little adaptations."

To read Nav's story, visit: colostomyuk.org/idpwd-not-all-disabilities-are-visible-nav-johal/

Vacancy: Clinical Trustee

Are you a healthcare professional actively working with stoma patients and the stoma community? We are looking for a registered practitioner to join our board of trustees. You will enhance Colostomy UK's understanding of the challenges clinicians face on a day–to–day basis and help us to forge productive relationships with the healthcare profession. Your input and guidance will shape our services, helping ostomates of today and tomorrow thrive and flourish. This is a voluntary position suitable for a senior clinician. Charity experience will be beneficial. To enquire please email: info@Colostomyuk.org

Have Your Say on the Companies Who Deliver Your Stoma Supplies

The British Healthcare Trades Association want to set up a patient panel to give feedback on the service they receive from pharmacies and dispensing appliance contractors. The latter are also sometimes known as DACS and are the companies who deliver your supplies.

The panel will consist of approximately 300 patients who have had a stoma for at least 12 months. Panel members must be willing to complete a 10–minute survey four times a year, about the service they have received around both ordering stoma supplies and having them delivered.

The British Healthcare Trades Association say: "We would welcome and value your honest feedback. 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."

You can register to take part through the following web link https://cfep.net/wKx3LR and once they have the full panel in place, the British Healthcare Trades Association will contact you with further background information on the survey objectives and process.

CAFE – Centre for Access to Football in Europe

We have been working with CAFE – Centre for Access to Football in Europe to look at inclusion for non–visibly disabled football spectators and spectators with long–term health conditions at football matches. Our General Manager, Libby Herbert joined the Expert Working Group to represent the needs of ostomates.

The survey revealed that people often face barriers due to a lack of consideration of, and provision for, their access requirements. Throughout the survey, respondents repeatedly gave examples of being challenged when using accessible services. 72 per cent of participants stated they have had their eligibility to use accessible services questioned at a football match or elsewhere. One fan with a stoma, described taking crutches to matches to save 'the embarrassment each time' and to reduce 'the risk of being turned away'.

Physical searching was a common barrier across differently disabled participants, with some people with stomas reporting that they found it embarrassing having to explain and expose their bags in front of other spectators.

Libby Herbert was delighted to support the project and said "[It is] an extremely well documented report, CAFE should be very proud of it."

CAFE have made recommendations and they will support stadiums to improve access and inclusion for non–visibly disabled fans, including ostomates, by creating training on innovative access solutions for governing bodies, national associations, and clubs.

Check out the full report here: https://www.cafefootball.eu/news/cafe-publishes-access-and-inclusion-for-non-visibly-disabled-spectators-and-spectators-with-long-term-health-conditions-report

eBay for Charity

When you sell your unwanted items on eBay you can donate a percentage of your sale to Colostomy UK.

Find out more at **colostomyuk.org/get-involved/ebay-for-charity/**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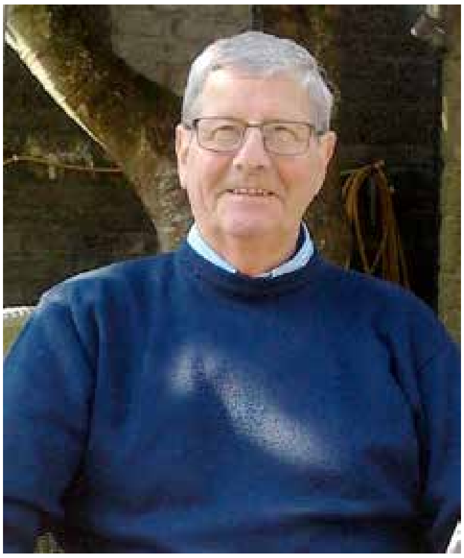
"Never been better…", I told my doctor: How wrong I was!

Ken Edwards



On Tuesday 30 October 2007, I had a routine appointment with my GP for a thyroid check–up. As I was about to leave the consulting room, I told him how fit I was feeling. I was back in the gym and feeling better than I had been for some time, except…I felt I had a little problem in the rear, piles or something, or perhaps it was just me getting older. He immediately called me back and got me on the bed and did an internal examination. Afterwards he said he would ring me in the afternoon at my work, as he was not happy. That afternoon he phoned to say that he had made an appointment for me at Salisbury Hospital on Friday 2 November. So off I went on the Friday, and after some initial tests I was diagnosed with suspected bowel cancer. I was told that in the following week I would have a CT scan, barium enema and an MRI scan. At the end of that week, I returned to the hospital for the results. I was asked to bring the wife.

On entering the waiting room I was ushered straight away into a consulting room to be confronted by six people and told it was not good news. I did indeed have bowel cancer and it had spread to the prostate as well. They said they would work as quickly as possible and were the team that was going to be treating me: a consultant surgeon, consultant colorectal surgeon, consultant urologist surgeon, consultant plastic surgeon, specialist nurse and a support nurse. They had arranged for me to go to Southampton Hospital the following week to see a consultant oncologist and start 12 weeks of chemotherapy. Talk about being fast tracked within a month of seeing my GP!

I started chemo in Southampton but still the news I had cancer was not really sinking in. The chemo was not at all pleasant in the first week, but I kept telling myself I must be positive and keep fit. So, I did still manage to get to the gym once a week. At the end of chemo I had more scans, then six weeks of intensive radiotherapy every day, which I found tiring and exhausting. However, because I was having the treatment first thing in the morning, I was managing to get back into work by the afternoon most days, and still go the gym as well. I kept telling myself I must keep fit. Then it was more scans and back to meeting with my team in Salisbury. This is when I was told how different my life would be.

I was to come back into hospital the next week for multiple, major surgeries. I had my whole prostate removed (prostatectomy) and rectum, anus and part of my large bowel removed (abdominoperineal resection). The extent of these procedures meant I needed reconstruction of my perineum and the creation of a flap to close up the wound (VRAM flap reconstruction of the perineum). It also led to the formation of two stomas: a colostomy and Mitrofanoff.

Mitrofanoff: This surgery avoids the need to wear a urostomy pouch. Instead a small stoma is created and a catheter is passed into a reservoir (or the natural bladder) to drain the urine. A urinary reservoir is fashioned from bowel, or the person's own bladder may be used as the reservoir. A channel is created from the appendix, ureter or ileum. The diversion is continent because of the valve arrangement, which prevents urinary leakage **(https://urostomyassociation.org.uk/information/mitrofanoff/)**

The pouch for the colostomy I coped with well, although it took a bit of time to adjust. Like many other ostomates, I found joining **Colostomy UK** and reading *Tidings* was a great help. But the mitrofanoff was a different matter altogether. Prior to the surgery I had not even heard the term, let alone what it referred to. Post–op, I learned I was not alone in my ignorance and discovered that few people (medical people included) were 'in the know'. As you can imagine, this had implications in terms of getting support!

I've been active all my life, and I liken it now to having three lives: one in the 60s in the pop world; then in the 70s, 80s and 90s in local politics; and now more recently in charity work. In my 'first life', I worked as a singer and did some acting. This started with me taking up guitar and singing in skiffle groups.

CONTINUED ON PAGE 15, COLUMN 1

CONTINUED FROM PAGE 13, COLUMN 2

In the 60s I was in a group called the Sceptres. This was followed by a solo spell in London, singing in clubs and other venues under the name of Richard Hudson. In my 'second life' I was an agent and councillor on both district and county councils. I suppose I was an early spin doctor dealing with the press and TV when I was running by–elections. I was Mayor of Salisbury in 1979–80 and later Chairman of the district council.

Then came my 'third life'… I had been involved in charity work in the past, volunteering for the MS Society and driving their ambulance bus (purchased for them as part of my mayoral appeal). But, given the circumstances I found myself in, I thought I should do something about finding support for those with a Mitrofanoff and so set about looking for others with a Mitrofanoff. In doing so, I came across Kyla Hooper, as she was then, who wanted to do the same. So we joined forces and in 2009 set up Mitrofanoff Support (gaining charity status in 2010). I became chairman and Kyla and I travelled the country raising awareness and attended nurses conferences, etc. And so Mitrofanoff Support was born and is still helping support those with a Mitrofanoff. I am now an advisor with the charity and, since setting it up have also joined the local Wessex Stoma Support Group. After a year I became their chairman (they must have seen me coming!) and my wife Pam is Welfare and Membership Secretary.

Colostomy UK

Not all disabilities are visible

#stomafriendly

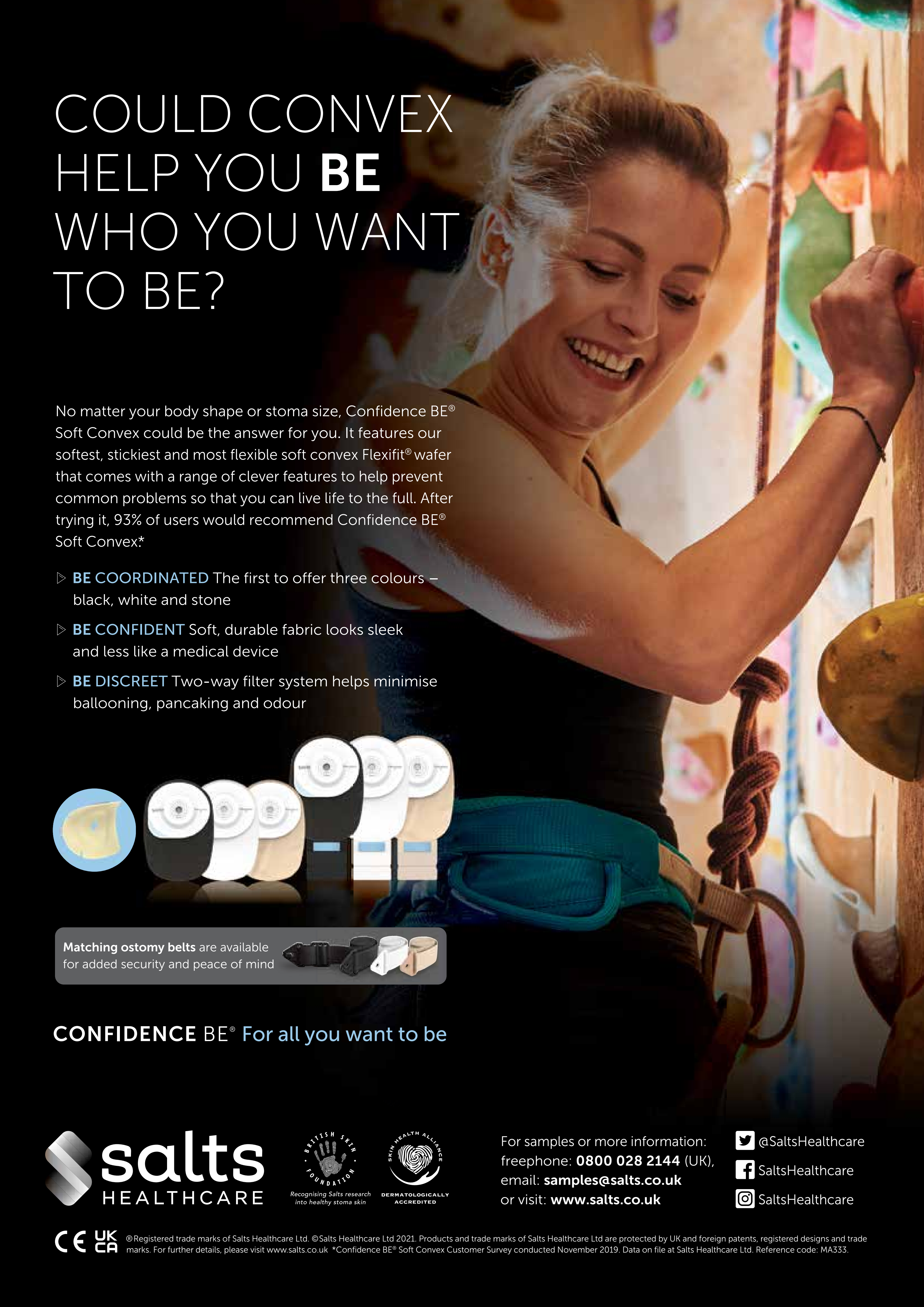
If you would like to make your organisation stoma friendly please get in touch by emailing: **info@ColostomyUK.org** or calling: **0118 939 1537.**

For more information on what makes a toilet 'stoma friendly' visit: **colostomyuk.org/wp-content/uploads/2020/09/Stoma-Friendly-Toilets-Guidelines.pdf**

During my first year or so of joining the group, I experienced abuse and harassment when leaving accessible toilets and found some toilets didn't have much in the way of facilities for people with stomas. This prompted me to start writing to venues, supermarkets and town councils asking them to make accessible toilets stoma friendly and spread the message that not all disabilities are visible. I have enjoyed some success with this campaigning, most notably with Salisbury becoming a stoma–friendly city. Having been a member of **Colostomy UK** since my surgery, I was thrilled to find that they too, along with Crohn's and Colitis UK and Changing Places, are campaigning for the same things. I know that collectively great steps forward have been made, although there is a lot more work to be done!

Wessex Stoma Support Group has also made great progress; membership now stands at nearly 100. With regular press releases and by working with **Colostomy UK** it is keeping stoma awareness to the forefront.

It has been a busy time since being diagnosed in 2007. Apart from a few problems with my Mitrofanoff in the first three years, I have been lucky. My surgery has allowed me the chance to continue living life to the full. I have kept my hand in entertaining, including being a model at a number of the **Colostomy UK** Open Day fashion shows. I have continued to travel. Since my surgery I have made three long trips to Canada to visit family living over there. I am a firm believer that keeping fit has helped. Similarly, I have found too, that getting involved and helping others goes a long way. The consultant surgeon told me after my operation: "We gave you six weeks at the start". But 13 years down the line and I am still here, causing chaos! I am greatly indebted to Hugh Bond my GP, who acted immediately upon my symptoms and referred me for urgent invesigations.



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Colostomy UK: volunteers

Emma Howell
Volunteers Manager
E: volunteer@ColostomyUK.org

Well, what a year we have had! When I think back to January 2020, as we planned to deliver face–to–face volunteer training in Kent and compare this with what actually happened and where we are now, I am stunned. I spent time reflecting on this over Christmas, thinking about the year's many 'Highs' and also, I'm sad to say, its 'Lows' as well. Thankfully, on balance, I think the former outweighed the latter. And I know that the scales settling in this way, had much to do with the ongoing enthusiasm and support of **Colostomy UK's** volunteers. With everyone's lives in flux, it would have been completely understandable if 'volunteering' had suffered. But not so at **Colostomy UK.** In fact, quite the opposite happened as our dedicated team rose to, and overcame, the many challenges Covid–19 posed us. As Volunteers' Manager, I will always be proud of the fact that we kept supporting ostomates in need not despite the pandemic but in spite of it! I thought I would share my 'Highs' and 'Lows' for year and also the 'Highs' and 'Lows' of our volunteers.

My Highs:

- Seeing a national focus on volunteers and celebrating the merits of volunteering and what volunteers can achieve supporting people in need.
- Connecting with our volunteers via Zoom/video. Being able to bring people together in this way was completely unexpected.
- Getting to know our team of volunteers better (helped by the above!!).
- Rolling out **Colostomy UK's** Safeguarding Adults programme, with a new policy and online training. This has led to greater awareness about safeguarding (what it is, why it is important, how to spot possible safeguarding concerns) across the charity as a whole.
- The launch of our **Telephone Befriending Service.**
- Managing to move our training to an online format. For a national charity being able to provide training in this way will be important even once the pandemic is over.

My Lows:

- Being forced to cancel the face–to–face training we had planned for March and later in the year. When we first made this decision, it was devastating as so much work had gone into preparing for it. Thankfully, we were able to salvage this!
- Not being able to meet our volunteers in person. Zoom is great, but it's not quite the same as being with people in the flesh.
- Having to suspend many of our volunteering activities, such as open days.
- Not managing to always meet the expectations of new volunteers and people interested in volunteering with us.

And here are some from our volunteers:

Highs:

- Hearing the immediate change in the voice of a caller to the Stoma helpline, you can hear the tension in their voice reduce. You may not always be able to solve their problem but just listening to what they have to say and pointing them in the right direction to help them help themselves is priceless for me as a volunteer.
- During the pandemic just being a part of **Colostomy UK** was good, it is just such a friendly team.
- When a lady I spoke to on the Stoma helpline who was feeling low said: "Thank you for being there, I feel better about myself now", at the end of the call.
- When someone calls back to say you have made a real difference.
- Taking part in **Colostomy UK's** Zoom meditation and yoga.
- Zoom made it possible for me to actually 'meet' with the rest of the *Tidings* editorial team. As well as proofreading articles, I have enjoyed being a part of all the lively discussions that take place when we meet to decide on the magazine's contents.
- Emma arranging the Zoom meetings to keep us volunteers in touch with each other and the **Colostomy UK** team and Richard and team for the excellent *Tidings* which has kept us informed in these uncertain times.

Lows:

- Not being able to see and help ostomates face to face at things like open days and support group meetings.
- Receiving Stoma helpline calls from ostomates who have run out of bags and then get angry when I'm unable to magic them some fresh supplies!!
- The pandemic made me realise how vulnerable we all are and how easily the balance of normality can tip in the wrong direction.

So there you have it!

It has been a real pleasure to work and get to know better **Colostomy UK's** volunteers and I am looking forward to what 2021 brings. If you would like to know more about volunteering for **Colostomy UK,** then please drop me an e–mail: **volunteer@ColostomyUK.org**

Emotion Regulation and Rumination in Inflammatory Bowel Disease:

Assessing the Effecting of Body Image Perceptions

Bethany Preece
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What was my research?

My MSc Health Psychology research dissertation involved exploring the extent to which emotion and overthinking affected body image satisfaction within an Inflammatory Bowel Disease (IBD) population. Body image dissatisfaction can manifest itself in several ways and can occasionally make it difficult to form personal relations as well as making social interactions daunting. Depending on the severity of the dissatisfaction, this can lead to social avoidance and may impact upon an individual's psychological health. Emotion was classified as emotion regulation techniques, which is the way individuals manage and control their emotions. This is achieved in a number of ways: it may involve confronting emotions head on and accepting feelings that accompany this in mindful way such as diary entries; distracting yourself from truly handling emotion by ignoring them; or even being able to prevent negative emotions from affecting your outlook altogether. Whilst this is considered similar to the idea of emotional coping, they are considered to be separate units. It can be described as a positive control of emotion, or cognitive reappraisal, within which individuals can successfully prevent the negative impacts of thought–provoking emotions such as anger and frustration. This is a more hands–on approach to ensure emotions are dealt with and accepted rather than bottling them up. On the other hand, it can be defined as a negative control of emotions, or expressive suppression, within which individuals hide and push down emotions in particularly emotion–eliciting situations, such as during a flare–up or whilst having a bad day at work (Cutili, 2014).

Overthinking was pinpointed to be defined as rumination in this study, which is considered to be repetitive reflection of emotionally triggering events and can develop into a transfixion on these thoughts. This can include scenarios such as excessively pondering the likelihood of a flare–up on the day of an important exam or convincing yourself that your boss will not enjoy your presentation before you have even delivered it. Previous research has indicated that rumination is more prominent in individuals who are living with a chronic illness. I was particularly interested in understanding whether there was any relationship between rumination levels and body image satisfaction in an IBD community, and how regulating emotion may alter these processes. It was also interesting to note that body image can be sub–divided into satisfaction and dissatisfaction with one's own body. Body image is a more complex variable than one might realise, due to a combination of factors including psychology, emotions, and individual behaviour, thereby indicating the complexity that arises when beginning to address this. As a result of IBD becoming a global public health challenge, I was curious to shed some light on the psychological processes that surround body image satisfaction within this community.

Why did I conduct this research?

Previously, body image dissatisfaction has been linked to unfavourable health outcomes, as well as the worsening of other physical symptoms in illnesses such as IBD (Nayir et al, 2016). As such, I found it particularly remarkable to note that body image satisfaction, emotion regulation and rumination had never been studied collectively within a population of individuals living with IBD. This is because IBD is such an unpredictable disease and, as readers of *Tidings* who suffer from it will know, ongoing self–management is often required to manage symptoms and control emotions. It was hoped that the results from this research could be used to inform a potential intervention within which individuals with IBD feel more readily able to effectively deal with negative emotion, therefore benefiting the course of associated physical and psychological symptoms. Consequently, due to the large degree of body image research conducted within an IBD community, combined with the fact that living with IBD can deter positive emotion regulation strategies (Danesh et al, 2015), the current research was incredibly important and necessary.

What did I do?

The results were obtained by presenting individuals with three online measures to complete. This was an anonymous survey, and individuals could not be identified through their responses. To be included in this study, participants were required to have had a diagnosis of IBD for at least three months, be aged 18 or over and be able to speak fluent English. Everyone who provided responses did so of their own free will, and thus volunteered to provide answers for the study. Participants were recruited through five IBD–based charities sharing the study within their social media and websites, one of which was **Colostomy UK,** who asked eligible members of their private Facebook group to participate. I also used my own professional Twitter account. Responses were recorded via the completion of the Modified Body Image Scale, the Emotion Regulation Questionnaire, and the Ruminative Responses Scale. Ethical approval was obtained from the Manchester Metropolitan University Ethics Committee on 2 April 2020, (EthOs ID number: 17132) and recruitment spanned over a three–month period. Subsequently, 231 participants aged between 18–77 years (172 females, 58 males and 1 non–binary individual) completed the survey for this project.

What did I find?

The data was analysed on a statistical software program to assess the degree of relationship between body image satisfaction, emotion regulation and rumination. Overall, it was found that suppressing emotions was linked to body image dissatisfaction, as well as greater levels of rumination. Individuals who are better able to ease the impacts of negative emotions exhibited greater body image satisfaction. However, body image dissatisfaction was a common theme within these findings, showing that individuals with IBD displayed lower levels of satisfaction with their body image overall. To further support this, when individuals were asked if they felt self–conscious about their appearance, only 8.2% (19) of 231 people in the sample indicated they did not feel at all self–conscious. Furthermore, when individuals were asked if they felt less sexually attractive as a result of their IBD or treatment, 87% (201) of individuals agreed with this statement to some extent (ranging from a little to very much so). 53.2% of people rating the account, 'I control my emotions by not expressing them,' agreed with the statement to varying degrees (whether this be slightly or strongly agreeing). This further corroborates a statement within the rumination scale, 'How often do you think: "Why can't I handle things better?"' 74.9% (173) of 231 individuals displayed some level of agreement with this statement. The most interesting statement however, alluded that 93.1% (215) of individuals felt dissatisfied with their body. This extends the work of other researchers, whilst also highlighting that negative emotion regulation strategies are more prominent within the IBD community.

What is the importance of this research?

This research indicates the degree of support required for emotional wellbeing in a long–term condition such as IBD. This is something that could potentially be addressed directly from diagnosis. IBD is a disease that is already associated with a greater developmental risk of anxiety and other such mood disorders, highlighting the importance of regulating emotions. Interventions to target the adoption of positive emotion regulation have previously proven to be effective, and emotion regulation training has shown continuing success in various settings. Building upon previous literature, these findings demonstrate the importance of addressing body image concerns. This is because emotion regulation is influential in the ability for an individual to deter negative body image connotations. This supports that of previous researchers, who indicated that body image concerns and unhelpful emotion regulation techniques are more prevalent in individuals living with a long–term physical illness.

The symptoms of IBD can produce an emotional burden on the individual, depending on the severity and the nature of the disease. Although this is still prevalent within the general population, it is to a lesser extent and without the additional stress of coping with a long–term physical illness. The importance of this research indicates that more care is needed to address psychological symptoms within an IBD community. A screening tool to determine this at diagnosis and at regular intervals following this may ensure individuals receive the support they need. It is worth noting that previous literature has highlighted the degree to which a stoma bag may influence an individual's body image ideals, and whilst this is not directly addressed within this research it is a way to expand upon this study. Despite this, current research promotes the benefits of adopting cognitive reappraisal to tackle emotions and body image complexities. Furthermore, this research may be the stepping stone to ensuring the mental and emotional health of individuals living with IBD is both supported, stabilised, and nurtured, particularly during these troubling times. ■

References

Please contact the author for a full list of references used in this article.

Cutuli, D (2014) *Cognitive reappraisal and expressive suppression strategies role in the emotion regulation: an overview on their modulatory effects and neural correlates.* Frontiers in System Neuroscience, 8(175), 175–181.

Danesh, M, Gholamrezaei, A, Torkzadeh, F, Mirbagher, L, Soluki, R and Emami, MH (2015) *Coping with stress in patients with inflammatory bowel disease and its relationship with disease activity, psychological disorders, and Quality of life.* International Journal of Body, Mind, & Culture, 2(2), 95–104.

Nayir, T, Uskun, E, Yürekli, MV, Devran, H, Çelik, A and Okyay, RA (2016) *Does body image affect quality of life?: A population–based study.* PloS one, 11(9), e0163290.

Colostomy UK: campaigns and projec

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#StomaAware

In the last edition of *Tidings* I explained how we used World Ostomy Awareness Day in October to launch our new #StomaAware campaign. Part of this campaign is to educate and work with organisations to ensure they understand the emotional and practical needs of ostomates. In our view, good education is key to making our society more accessible to all.

With this in mind, it was great to start the ball rolling in early December delivering some **#StomaAware** training to the team at Bolt Burdon Kemp (BBK), who are a firm of solicitors I have worked closely with over the past few years. I was delighted to be joined by Ifrah Mohamed who, as an ostomate, was able to highlight to attendees what daily life is like for somebody living with a stoma. Our training also looked at why people have stoma surgery and considered the struggles many face afterwards such as fears about returning to work and using accessible toilets. Iffy was able to explain how important it is after surgery to get back to 'normal' and how doing so can aid long–term recovery and ongoing quality of life.

Our role as a charity is to help reduce the hostility, discrimination and prejudice some ostomates experience. The team at BBK asked lots of questions and were keen to get a good understanding from Ifrah about her life with a stoma and the impact her surgery had. Below you will find two articles from members of the BBK team, as well as Iffy's closing thoughts on the training session. I hope you enjoy reading them. They show why being **#StomaAware** is so vital!

Bolt Burdon Kemp

My eyes were opened

Tom Lax

My first experience of someone with a stoma (or someone who I knew had a stoma) was as a trainee solicitor. I attended a conference with her, her son, numerous experts and a senior barrister. She had suffered an injury due to medical negligence and the purpose of the conference was to work out the value of the claim by discussing the impact of the injury on her ability to work and care for herself.

My eyes were opened hearing about the mechanics of the ileostomy operation and the lifesaving impact it had had, but also by the way having a stoma had affected her physically and emotionally.

That case settled for an amount in excess of £500,000, which meant that the client's son could work part time and become his mum's carer. I was inspired to start my career in compensating victims of medical negligence and captivated by the physical and emotional plight of ostomates.

Years later I got in touch with **Colostomy UK** to undertake some fundraising for their 'Fight the Poo Taboo' campaign. Whilst doing that, and in the four years since, I have learned so much about the small things society can do to improve the lives of the thousands of people who have this hidden disability. The biggest lesson of all being that educating ourselves is crucial if we are to make the country more stoma–friendly and fight the stigma that has caused so much distress.

Last month, therefore, I was delighted to invite Libby Herbert to my firm, Bolt Burdon Kemp to host a 'Stoma Aware event'.

She attended with Ifrah Mohammed (an ostomate she has met through her work) to educate me and my colleagues about the basics of having a stoma and the issues that impact a lot of the people who have one.

The feedback I received from all who attended was glowing. We learned about the small things that could make a big difference to ostomates – from stoma–friendly toilets (hook, bin, shelf, mirror!) to appropriate conduct at airport security. Mostly though, we were privileged to an honest, open portrayal of life with a stoma from several different angles.

Libby spoke with the kind but determined enthusiasm I have grown to admire since we connected.

Ifrah's part of the event was impassioned and inspirational. A full–on account of the events leading up to her ileostomy and her life afterwards. Authentic, unscripted and impactful. Perhaps the most incredible part was the story of her pregnancy – doctors had told her that it would not be safe but she weathered the pain and the risks to give birth to a boisterous daughter we could all hear running around in the background as we sat gripped to our Zoom screens.

After this Rhicha Kapila, a partner at Bolt Burdon Kemp, talked about her experiences of caring for her mum who recently had a stoma sited as a result of a cancer operation. Hearing someone we all knew and respected professionally talk about the resounding personal, hidden impact of these operations hit home how close we all were to someone who had been affected.

ts

And…time and again…whilst the varying physical impact on day–to–day life was made clear (going on holiday or to the swimming pool, contact sports, or out for dinner) it was the social and emotional impact of these amazing life–saving surgeries that hit home – it is on all of us to break down the stigma that erodes the life of people who have enough to deal with already.

The work of **Colostomy UK** is crucial. So much can be changed in the lives of so many by the hard work of a few people to shift attitudes.

All my colleagues work for clients who have suffered serious injuries. Our cumulative experience of acting for the physically disadvantaged is vast but we still had a lot to learn. We can now take that learning into our work and our lives.

Bolt
Burdon
Kemp

Do I have a stoma?

Rhicha Kapila

When we first heard the news that Mum's stage 2b ovarian cancer had reoccurred in early 2020, following four years of remission, my family and I were gutted. To remove the new tumour, snug between the rectum and vaginal wall, it was necessary for Mum to have major exploratory surgery. We were told there was no certainty that it could be removed successfully.

During our early conversations with her gynaecological surgeon, we consented to a stoma but were told this would be a last resort and in all likeliness reversible. The uncertainty meant that she wasn't introduced to a stoma specialist nurse, neither was her stoma sited ahead of surgery. In some ways, Mum was more fearful of living a life with a stoma than the cancer reoccurring.

After seven long hours on the operating table, I received a call from her surgeon. He confirmed it was more complex than anticipated, but it was positive news – he had removed the tumour with good margins. He had to perform an end colostomy to get to it, which was now irreversible. There was also talk of him having to insert a kidney stent. All that sunk in was mum's lifesaving surgery had been a success. I was beyond relieved.

It was the first 2020 lockdown in March which meant no hospital visits. The first thing she asked when she came round was: "do I have a stoma? Is it permanent?". The immediate aftermath post–surgery was tricky with pain control, wind, sickness, inability to eat and waiting for the paralysed bowel to start functioning again, which are all common issues. It took some time before she was able to look down at her new stoma. The NHS stoma bags are not prescription based, and much larger and visible. This is what Mum thought she now had to live with. You see, it's not just dealing with a new physical norm, it's getting your head around it emotionally. I picked her up from hospital after ten long days to bring her home weighing less than 38kg (six stone).

Lockdown meant no regular home visits from the stoma specialist nurses which is the usual pathway. I decided to take care of the practical side of things, so she could just focus on recovering. She had six rounds of chemotherapy ahead of her.

I formed a support bubble with Mum under the government's COVID rules. I was lucky to be able to support her, but I knew I needed educating and fast. I started to read a couple of leaflets handed to us about foods to avoid, blockages, constipation, leakages, ballooning, pancaking all of which was quite overwhelming.

Mum was discharged with a bag of prescription items from Coloplast Charter which included: SenSura Mio 1–piece open, barrier wipes, adhesive sprays, wipes and disposable bags. These are essential items that she would need daily. I emptied a drawer and organised all of her products so they were easily accessible. Then, of course, I had to order her a posh bag online so she could carry her products in style! That was the easy bit done. The rest needed a bit more research.

The first few weeks were met with frustration. I was shocked by how little some GPs knew about stomas. Our prescription was even initially confused with catheters. It did eventually get easier and having supplies delivered directly to the door is really helpful.

I first came across **Colostomy UK** on Facebook. I cannot tell you how useful this resource is and how it became a 'game changer' for mum and I. All of a sudden, we had instant access to fellow ostomates with a fountain of knowledge and experience who seemed to have all the answers! Within minutes of a post, we would receive dozens of helpful replies.

Libby has been fantastic too. Until I spoke to her I had no idea that ostomates actually have 'choices'. We didn't even know that stoma bags come pre–cut once the stoma has settled in size. I had spent months cutting hundreds of them by hand to size. I also realised that the stoma bag Mum was prescribed (SenSura Mio drainable) should be used by those with an ileostomy and not a colostomy. We had the wrong product prescribed. We've since sampled other stoma bags, which we didn't know we could do, including Salts 'Confidence Be' and Coloplast 'Mio Concave', which should also stop the itchiness as some ostomates become allergic to the base plate. Mum suffers with soreness and a constant itch so changing the product is a vital option. Different types of barrier wipes and calamine lotion all help too. Yes, you guessed it, all this advice came from **Colostomy UK.** We were none the wiser.

Unfortunately, one in three people with stomas go on to develop a hernia at some stage in their lives. If the bowel becomes strangulated, it can be very dangerous. Mum's latest CT scan shows evidence of a hernia forming, which is now becoming more visible as the stoma protrudes. Libby sent Mum a really informative leaflet on it. Until then we had no idea that she is entitled to prescription based support products. We've now ordered a hernia support belt and girdle via CUI wear which should help. Apparently surgery isn't an option, unless symptoms worsen, as there's a real risk a hernia could redevelop under the stoma even after a repair.

This is just the tip of the iceberg, there's been so much information ostomates have shared with us on the **Colostomy UK** Facebook page that has been incredibly useful to us.

CONTINUED ON PAGE 22, COLUMN 1

CONTINUED FROM PAGE 21, COLUMN 2

For example, tips on what clothes to wear to help disguise the stoma bag (high–waisted briefs and leggings/support vests/patterned tops). Pointing us in the direction of glycerin suppositories instead of irrigation to control mucus, again something our GP couldn't help with. To who knew that 'full fat coke' was the answer to constipation in ostomates?

I am so thankful to **Colostomy UK**, and Libby, for such an invaluable resource and instant access to vital information. It's so important to families like mine, who have come to realise very quickly there is little stoma support out there. We're yet to see the stoma care team in clinic due to COVID, but we've been well supported by this charity. With many 'firsts' ahead of us (we are all hoping for a better 2021) like travelling abroad, airport security, swimming, and days out where Mum will need to use public toilets, there are still many unknowns ahead. However, **Colostomy UK** has helped my mum feel much more confident that living with a permanent stoma – still means living life to the full.

It was really heartening for me to hear from Libby and Iffy at our 'Stoma Awareness' event held at my firm Bolt Burdon Kemp organised by one of our Associates, Tom Lax. It really is time to break the stoma stigma in a positive way and educate ourselves. You never quite know when this hidden disability will touch our lives in such a personal way. ■

*Tom Lax and Rhicha Kapila are solicitors at Bolt Burdon Kemp (where Rhicha is also a Partner). Bolt Burdon Kemp is a leading nationwide law firm which specialises in bringing claims on behalf of people who have suffered serious injuries as a result of negligence. All the solicitors at Bolt Burdon Kemp are passionate about increasing awareness of the issues facing their clients and injured people throughout the country. You will find their website at **www.boltburdonkemp.co.uk***

Iffy's closing comments…

Ifrah Mohamed

"By educating people about the challenges we ostomates face it is hoped that positive changes will be made. And it works. If people or business owners don't know about the problems that people with hidden disabilities/stomas face, they are unlikely to make any changes. Good education and awareness is key to making our society more accessible for all.

I really enjoyed the stoma awareness training we did with BBK; I found it very productive. The questions and dialogue that I had with the BBK team was very informative and I felt like they genuinely wanted to know how they could work better with clients that have an ostomy/hidden disability."

Do you work for an organisation that needs Stoma Aware training?

If you do, then please get in touch by e–mailing **info@ColostomyUK.org**

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Colostomy UK: active ostomates®

Giovanni Cinque
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Welcome to the regular update page dedicated to our 'Active Ostomates' project.

'Active Ostomates' supports your wellbeing with a range of programmes. Some are delivered through support groups; some can be done in your own home; others you need to sign up for. We will also be promoting activities and events that can help everyone work towards having a more active body and mind.

Active Ostomates: at Home

Our 'Active Ostomates: at Home' classes have been running since April last year. We introduced them in response to the pandemic and they are a great way to exercise in the safety of your own home. We've been delighted by the numbers of people joining us online for chair yoga, yoga, dance, and mindfulness and meditation sessions. We also run art classes as well, to keep you mentally active!

Classes are held regularly throughout the year, using Zoom. The next set will be announced very soon, so take a look at our website for dates and times. Alternatively, you can sign up to our e–mail newsletter. Just visit our website and click 'e–newsletter' to start receiving monthly updates direct to your inbox.

Mindfulness and Meditation

Suitable for complete beginners as well as regular meditators, these 30–minute classes are fully guided. They aim to support you to find calm and ease in your life, no matter what is going on by teaching breathing techniques, body relaxation and mindfulness.

Yoga

Down to earth and accessible, the focus is on useful ways to move and breathe. A typical class will include body awareness, breathing techniques, preparing the joints, mindful slow–flowing movements, postures, meditation, and relaxation.

Pop to the '80s dance

Music and movement are two proven ways to improve your physical and mental health. These fun–filled 30–minute low impact fitness classes will have you dancing along to the best pop tracks from the last 40 years. The focus is on staying active, breaking a sweat, and having fun in a safe environment. No equipment is needed (except maybe a pair of trainers). We recommend that you wear a support belt or garment while you bop!

Chair yoga

Classes are suitable for people of all ages and abilities and focus on relaxation, movement and breathing techniques. All you need is a chair that you are comfortable sitting on!

Art

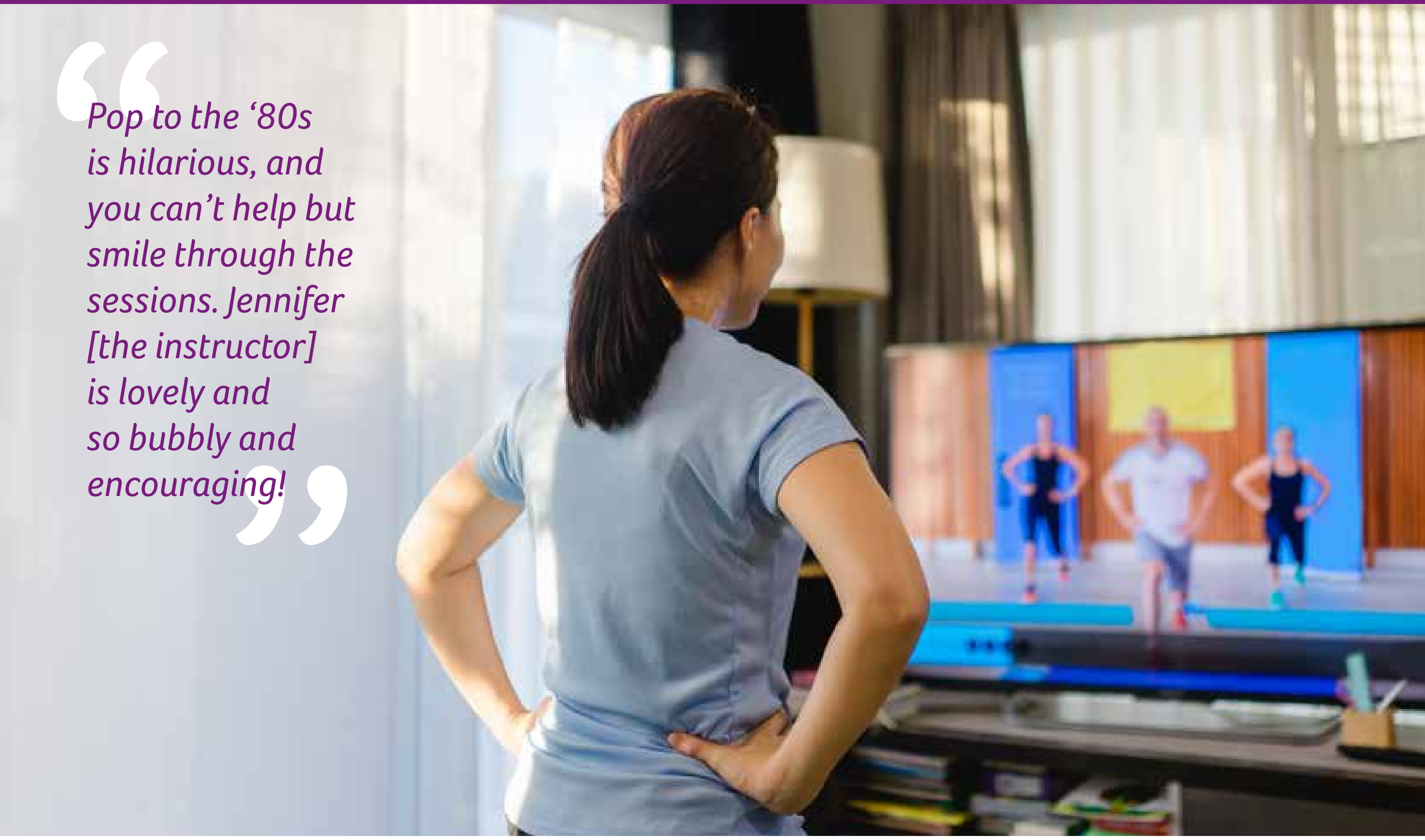
Our art classes tackle something different: getting your mind active. Each block of classes focuses on a new activity, from drawing to watercolours and block print, we are sure there'll be something for you.

If you'd like to find out more and book your place on a class just visit our website at: ColostomyUK.org/active-ostomates/

Look the part while working out - new merchandise

We're hoping our Team Colostomy UK Rugby League team may be back on the pitch later in the year. In the meantime, check out our great range of new merchandise including hooded sweatshirts, training shirts and match jerseys. They are all available to buy now online: **ColostomyUK.bigcartel.com/**

#ActiveOstomates



> *Pop to the '80s is hilarious, and you can't help but smile through the sessions. Jennifer [the instructor] is lovely and so bubbly and encouraging!*

The benefits of exercise - preventing parastomal hernias

Being active and, in particular, doing things that strengthen your 'core' is very important when you have a stoma. Your 'core' comprises your abdominal area, abdominal muscles (through which the stoma protrudes) and spine. The benefits of a strong core are many and include better posture and increased body awareness, while exercise in general generates a feel–good factor as well as keeping the pounds off. Importantly, strengthening your core muscles, along with keeping your weight in check can help to prevent parastomal hernias from forming.

Parastomal hernias occur when the edges of the stoma come away from the muscle, allowing abdominal contents (usually a section of bowel) to bulge out. Having a parastomal hernia, doesn't mean you can't exercise.

But at Colostomy UK we know that many ostomates (both with and without hernias) worry about what sort of exercises are safe for them to do.

In fact, we launched our Active Ostomates project partly to address these concerns and do all we could to get people with stomas active! After stoma surgery you should allow yourself time to recover, then provided you have an agreement from your doctor or stoma care nurse, you can introduce exercise and carefully build the intensity. Walking, running, dancing, swimming, and cycling are good starting points, but in time it is possible to do any sport or exercise. If you have a hernia, then your healthcare team will be able to advise you further, but rest assured they will be keen for you to exercise!

To read more about parastomal hernias download our booklet from our website. Alternatively call us on: 0118 939 1537 or for a copy email: info@ColostomyUK.org

Colostomy UK's very own Active Ostomates Sport and fitness after stoma surgery booklet includes a series of exercises that encourage core strength and can be repeated daily.

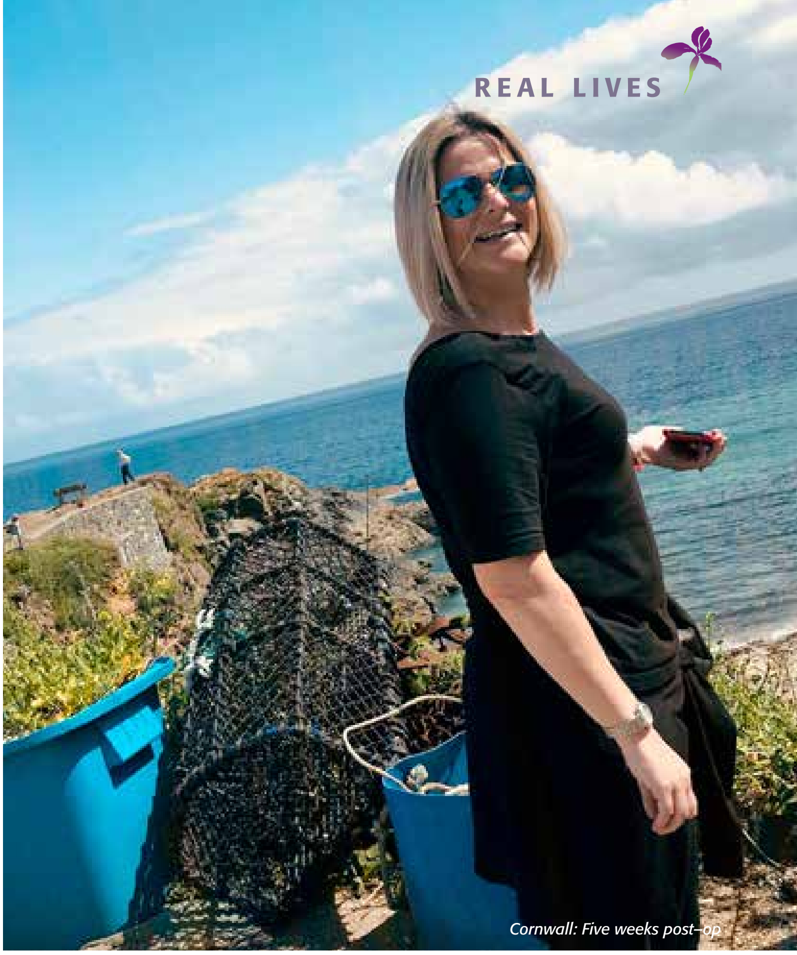
Each of them works deeply, increasing the strength of your back and stomach muscles, helping to reduce back and posture problems as well as the risk of post–operative hernias. The exercises can be performed on the bed, lying on a thick mat so that your spine is gently cushioned, or sitting on a chair. Some can even be done while you are watching the television!

You can download your free copy at: colostomyuk.org/active-ostomates/ You can also call us on: 0118 939 1537 or e–mail: info@ColostomyUK.org for a copy.


SOS

I will not be beaten

Lizzie Whitchurch


Cornwall: Five weeks post–op

Back in early August I interviewed a young woman. I remember the day well. This wasn't just because the sun was shining, and it was my 30th wedding anniversary. Nor was it just because things were beginning to feel normal again, having been back in the **Colostomy UK** office for a week or so. Instead, I remember the day as much as anything because of how I felt when I put the phone down: inspired. I know we are always hearing about inspirational people and inspirational stories. In fact, the word 'inspirational' has lost currency through overuse. But in Lizzie Whitchurch's case it's apt. Her story is one of pure grit and courage. Plagued by Crohn's disease since her mid–teens, she has undergone countless surgeries and come back each time fighting harder, utterly determined to suck the marrow out of life.

Lizzie was diagnosed with Crohn's back in 1998 when she was 16 years old. It followed a year or so of being told that the symptoms she was experiencing were down to irritable bowel syndrome. Finally getting the right diagnosis meant appropriate treatment could begin. But, even with this underway, Lizzie's symptoms got steadily worse. During 2002 she was admitted to hospital every single month of the year. Things escalated from here and in 2005 she had resection surgery. Post–op, the initial signs were encouraging, but about eight months down the line Lizzie started to feel very poorly again. Although her healthcare team thought it was Crohn's, Lizzie wasn't so sure. As she said when we spoke: "I knew it wasn't the same pain". Several hospital visits later and following a day in which the pain became almost unbearable, it was discovered that the problem lay with Lizzie's ovaries. This led to Lizzie having emergency surgery in February 2006 when a large abscess on her ovary burst. The whole episode turned in to something of a nightmare. She had a massive infection in her pelvis and needed to have an ovary and one of her Fallopian tubes removed. The surgeons also uncovered other issues, including severe endometriosis and polycystic ovaries. As she lay in her hospital bed afterwards, Lizzie was given the news many young women dread: having children was likely to be tricky.

A year later in 2007, Lizzie married Mark. They first met back in 2003. Mark had two young sons from a previous relationship (age five and age two and a half) and so the boys had already grown accustomed to Lizzie's health by the time of the happy day. Sadly, it wasn't long before Lizzie was unwell again. Eighteen months after the wedding she started to experience pain in the same side she had before. This resulted in another hospital admission and more surgery, this time to remove a cyst on her ovary. She was also put into a 'pretend' temporary menopause in order to rest things prior to starting IVF treatment. In 2011, after three rounds of this, Lizzie was told that due to her Crohn's she just didn't 'make a good oven'. The couple were obviously heartbroken by the news that they couldn't have children together, but rather than dwell on this Lizzie, who considers herself to be a cup–half–full kind of person, resolved to move forward. The family bought Purdy, their dog and focused on planning and enjoying holidays, which is (and was) something that Lizzie, Mark and the boys all live for.

Ill health hadn't finished with Lizzie though. As 2015 drew to a close it threw her another curve ball. Lizzie, who at the time was working for a social enterprise in Devon helping businesses and individuals across the south west to embrace technology, started to suffer again with pain and fatigue. While she loved the job, it was becoming increasingly clear that standing up in front of lots of people and providing training was taking its toll; she was exhausted. In February 2016 Lizzie was referred to Ian Daniels. As readers will know, Ian Daniels, who is a consultant colorectal surgeon at the Royal Devon and Exeter Hospital, is also the president of **Colostomy UK.** It was decided that Lizzie needed a further resection. Ian performed the surgery. Given Lizzie's medical history, it was expected to be complicated. Afterwards, he warned her that due to numerous adhesions sticking her organs together, she must never let a surgeon perform keyhole surgery on her, as it would be too dangerous. Lizzie took longer to recover than after her resection in 2005. In fact, she never fully got back to normal. Mornings had always been terrible

CONTINUED ON PAGE 29, COLUMN 1


S.T.A.R.S.

Lizzie and husband, Mark, Kayaking at Exeter Quay

Cambodia

CONTINUED FROM PAGE 27, COLUMN 3

for her needing the loo, and this situation began to noticeably worsen. Over time the pain started again too and began to restrict Lizzie from going out.

By the end of 2018, the situation was becoming intolerable. In the lead up to Christmas Lizzie became quite ill and started to need a lot of pain relief. This turn for the worse couldn't have come at a more inconvenient time, coinciding as it did with a once in a lifetime holiday to Cambodia, that had been months in the planning (and saving!). Ultimately, they decided to go, with Lizzie having an MRI scan days before departure. The holiday started in Bangkok, with the plan being to take in all the temples and other sights, before finishing with a beach holiday in Khao Lak. Lizzie was ill the whole time. Excursions were cut short so she could rush back to the hotel and all those idyllic walks planned along the beach Mark ended up doing alone. Looking back, Lizzie now admits it was a mistake to go.

On arrival back in London she was greeted with an urgent message from the hospital telling her to stop eating solid food. She was told the MRI had showed that her insides were so inflamed there was barely a big enough hole to allow the passage of food. When she met with her consultant to discuss the way forward, the conversation moved to the subject of having a bag. I asked Lizzie if she could recall how she felt about this and she replied 'excited'. When I queried such a reaction, Lizzie explained that after so many years of chronic illness, the prospect that this might go away left her elated. She was thrilled by the prospect of holidays without drama, being able to attend music festivals again and generally excited about what life for her might become without the shackles of Crohn's always there to restrain her.

Lizzie's stoma surgery was scheduled for April 2019, although she ended up being admitted to hospital the month before this. Ian Daniels performed the surgery, and all went to plan, with Lizzie being discharged just over a week later. Since then she has had a couple of setbacks. Her stoma retracted and had to be re–sited, meaning her colostomy can no longer be reversed. She has also suffered an infection around her stoma site. In July 2020 this required a small operation. But, given Lizzie's broader history, you won't be surprised to hear that she has taken all this in her stride. She was very upbeat when we spoke. She explained that although sorting her diet had been tricky to start with this had now settled down. She also has more control over when she needs to visit the toilet. She was proud to tell me that in the last 14 months she has only suffered three leaks. According to Lizzie "Life is blimmin' good. My story is quite long–winded and there has been lots of rubbish stuff but my life is great! I am very happy and live everyday with as much fun as possible." She went on to say: "I don't love my bag, but I love the freedom it has given me. I have walked on the beach. I go for walks. We go on holidays. I enjoy the odd gin and tonic."

So what makes some people respond to the prospect of stoma surgery and embrace life with a stoma in the way that Lizzie has? It's a question I have asked myself many times. As we all know, not everyone finds it possible to be so positive when faced with such enormous challenges. I get down in dumps just from having a cold. When I put this to Lizzie the response was enlightening. To begin with, she cited the fact that she has always been positive and has always been determined to enjoy life. This mindset she believes helped her to focus on getting better (and what this would mean for her future) rather than dwelling on being ill. She also felt that support from her family and friends played a crucial role in helping her to maintain such an outlook. With each setback, she said she became more bloody–minded and determined to get better and get the better of Crohn's. Something she said she has never wanted is sympathy. Lizzie is not the first person I have interviewed who has said similar about their battles with ill health. Chris Morrison whose story we covered in the last edition managed to get through his ordeal by focusing on the end result – e.g. getting back to work for the fire service rather than the illness that had put his life and that of his family's on hold. Our hope at **Colostomy UK** is that by sharing stories such as Lizzie's we can give encouragement to those who are perhaps at the beginning of their journey. As Lizzie said to me: "I will not be beaten. I love life. I have missed out on much in the past and I am determined to rectify this. I am not going to be locked in the house or locked in a body. I deserve more."

I could only agree.

written by **Richard Biddle**

PS: Since we spoke in August, Lizzie has given me a further update. She explained how her confidence has continued to grow and she feels her stoma has given her a new lease of life. She and her husband bought a kayak in the summer and on spare days explored the south coast of Devon. She has done a lot of walking during lockdown too, which is something that quite simply wasn't possible before. She has also signed up with a local gym and through exercise is both losing weight and focusing on strengthening her core (you can read about the importance of this for ostomates on page 24).

From baby, to bag and beyond!

Gillian Castle

July 2020. The door opened and I was pushed out screaming, the air pressing against my face as I felt my stomach somersaulting and hair whipping wildly in the wind. Thirty seconds of 322kph (200mph) freefall before the parachute triggered and I began to float down slowly, gazing at the tiny houses and cars below as my stomach gently swished. I couldn't believe I had done it: jumped out of a plane at 4.53km (15,000ft), with my crippling fear of heights! As I landed I felt elated, proud and powerful. I really could do anything.

In the car on the way home from the parachute centre, I thought about all the things I had managed to achieve since the autumn of 2011, when the traumatic early birth of my son had resulted in severe perinatal injuries, and a permanent colostomy. I had completed triathlons, culminating in a Half Ironman in May 2017. I had carried out other physical exploits, including a 169km (105miles) race from east to west Scotland, running, cycling and kayaking over a stormy September weekend. Open water swimming was a huge fear of mine, but something I so badly wanted to conquer… and I was now a regular sea swimmer, relishing the endorphins that only cold water can give on a grey winter's day. A long held dream was to become a diver, something I accomplished in late 2020. I had overcome my anxiety about wearing my bag out in public, with a bikini swimming challenge. I had spoken on BBC radio Newcastle about life with a stoma after childbirth. I had also become an enthusiastic road cyclist. I had come a long way since those first dreadful days in October 2011.

Waking up on the first rest day after seven days working in my much loved job as a police officer, I was hit by a sharp pain, my baby signalling that he was on his way at only 34 weeks gestation. My husband, Chris, gathered our hospital bags and we made our way to the hospital. It was 20 October 2011. Several hours later, after three attempted epidurals and a hasty forceps delivery when the baby got stuck in the birthing canal, to our joy our tiny 2kg (4lb 7oz) baby boy arrived. Sam was perfect, and after a quick check over by the special care ward, he was handed over to his anxious new parents.

Once the epidural wore off, I realised I was in huge pain and discomfort from the tear which the doctor informed me I had suffered. Assured that this level of pain was normal, I concentrated my energy on my little baby, learning how to feed him through the tube inserted up his nose. I kept a diary and excerpts from it reflect the true reality of what was happening to me, a grim tale of escalating pain, trauma and medical negligence. Over the next few days, around the tear became extremely hot, hard and painful, so much so that I recorded in my diary on 24 October: 'I was in agony going to the toilet to pass faeces. I had to be helped from the toilet and someone pulled the emergency buzzer for me. I was extremely distressed and told one midwife… that there was faeces coming from somewhere and I didn't know where and didn't even know where my anus was. I was in severe pain sitting down and trying to breast feed and express. A blood clot also burst when I was on the toilet and I was in great pain. It was quite frightening because I knew something was wrong with my body and I did not know what, and I began to dread going to the toilet because of the pain.'

In the ensuing days the staff realised that something wasn't right, and I was eventually examined under gas and air by a doctor, who diagnosed a recto–vaginal fistula, abscess and 4th degree tear. The only option was to have a colostomy to divert faeces away from the wound to help it heal. I was devastated. I didn't even fully understand what a colostomy was. All I knew was that I didn't want to have a bag of poo hanging down my leg as I walked about. I was horrified and couldn't believe this was necessary after having a baby. The first morning after my operation, I woke up to feel something warm spreading all over me. My bag had leaked poo, covering the bed sheets, my clothes, my stomach, and my legs. I was mortified, and utterly distraught that I had this awful contraption attached to me. Pressing the buzzer for assistance I knew then how completely my life had changed.

Two weeks after the birth, Sam and I finally went home. I found this totally overwhelming, wondering how I was going to manage a new–born baby and a new colostomy bag. The bag affected all parts of my life. In my journal entry for 4 November I wrote that Chris and I 'were lying in bed cuddling when all of a sudden the bag filled and leaked everywhere. I had to rush out of bed and change my clothes which were covered in faeces. It was very humiliating, and I felt a bit depressed that day about it all.' The effect on our relationship, both physical and mental, played on my mind for a long time, but fortunately Chris was extremely patient, understanding, and supportive. Sex was not something which

I was interested in at all for many months. I was too self–conscious about pressing my bag against his body, to want to even try it. Eventually I found some waist wraps, which I used to cover my bag and stop it flapping about when moving. In late November 2013, I discovered I was pregnant. Tragically, I lost the baby at 11 weeks in January 2014.

Trips to the shops were very stressful, several times these had to be aborted when my bag leaked. On 4 January 2012, the day after I found out that my colostomy would be permanent, I recorded how, during a shopping trip: 'the bag suddenly filled with runny fluid and I had to shout to Chris to grab Sam's pushchair which I was holding while I frantically rushed to the nearest bar. This was closed so I ran up the street and into a shopping centre, running into an empty bar to use the toilet. It gushed out everywhere when I opened the bag and I had to clean up the toilet seat and floor.

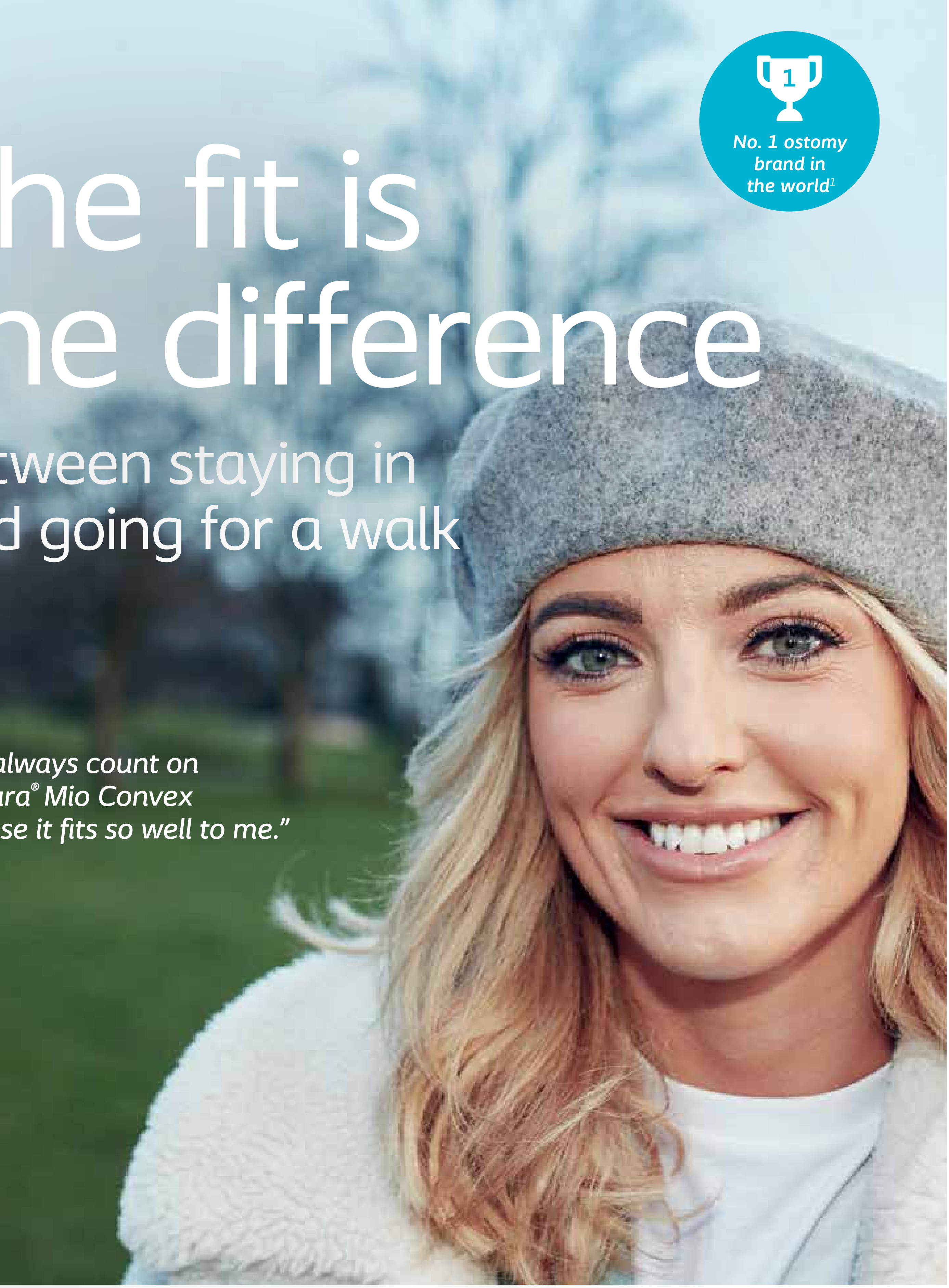
It was so close to me not getting there on time! Very stressful and embarrassing. I hate it…It's always on my mind and I'm getting really fed up with the whole thing.'

Fast forward to May 2013, when I was trawling through yet more internet forums, becoming increasingly depressed at the misery I found, when I saw someone write that they were grateful for their stoma bag, because without it they would be incontinent. The bag had actually given them a life. This was no light bulb moment for me, but a floodlight! Immediately, I imagined what my life would be like without my bag. I would be faecally incontinent, unable to leave the house and wearing adult nappies. With my bag, I was able to go shopping, walking, even swimming. I began researching how far stoma care had come since the mid 1950s, when stoma bags were bulky, awful contraptions. New bags are lightweight, waterproof, discreet. I suddenly felt euphoric. My bag had given me so much! The stoma had taken away my job, but there was so much I wanted to do.

From that moment on, I resolved to start living my life as I had always wanted. I started saying 'yes' to trying things, instead of saying 'no', deciding that if this was what I was given, then I was going to make the most of it. I saw an advert for a cycling class, and pushing aside my fears about toilet facilities, bag leaks and noises, I went to a session. I was hooked. I met members of the local triathlon club, and decided to give a triathlon a go, which led to open water swimming.

I have never looked back. In July 2020 I set up a website and Facebook blog, the Stoma Chameleon, a positive, warts and all site, aimed at inspiring people living with stomas and/or birth trauma. A chameleon adapts to its environment and so can we. In a way, having a stoma is the best thing to have happened to me, because it made me realise that life can change in an instant, and so if you want to try something – do it! Don't be afraid of failure. It's very empowering to realise what we are capable of, which is pretty much anything. I don't let my bag hold me back, and nor should you. Go out there and grab what life can offer before it's too late!

Editor's note: Gill's website can be found at **https://www.stomachameleon.com/** Just like her story, it's a truly inspirational and motivating place to visit!



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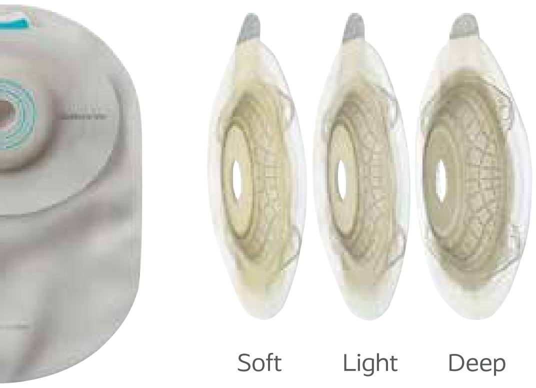

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1. SenSura Mio market shares, Coloplast, Data on file, PM-11253

2. Walker et. al. Raising the bar: new flexible convex ostomy appliance – a randomised controlled trial. WCET supplement 2016

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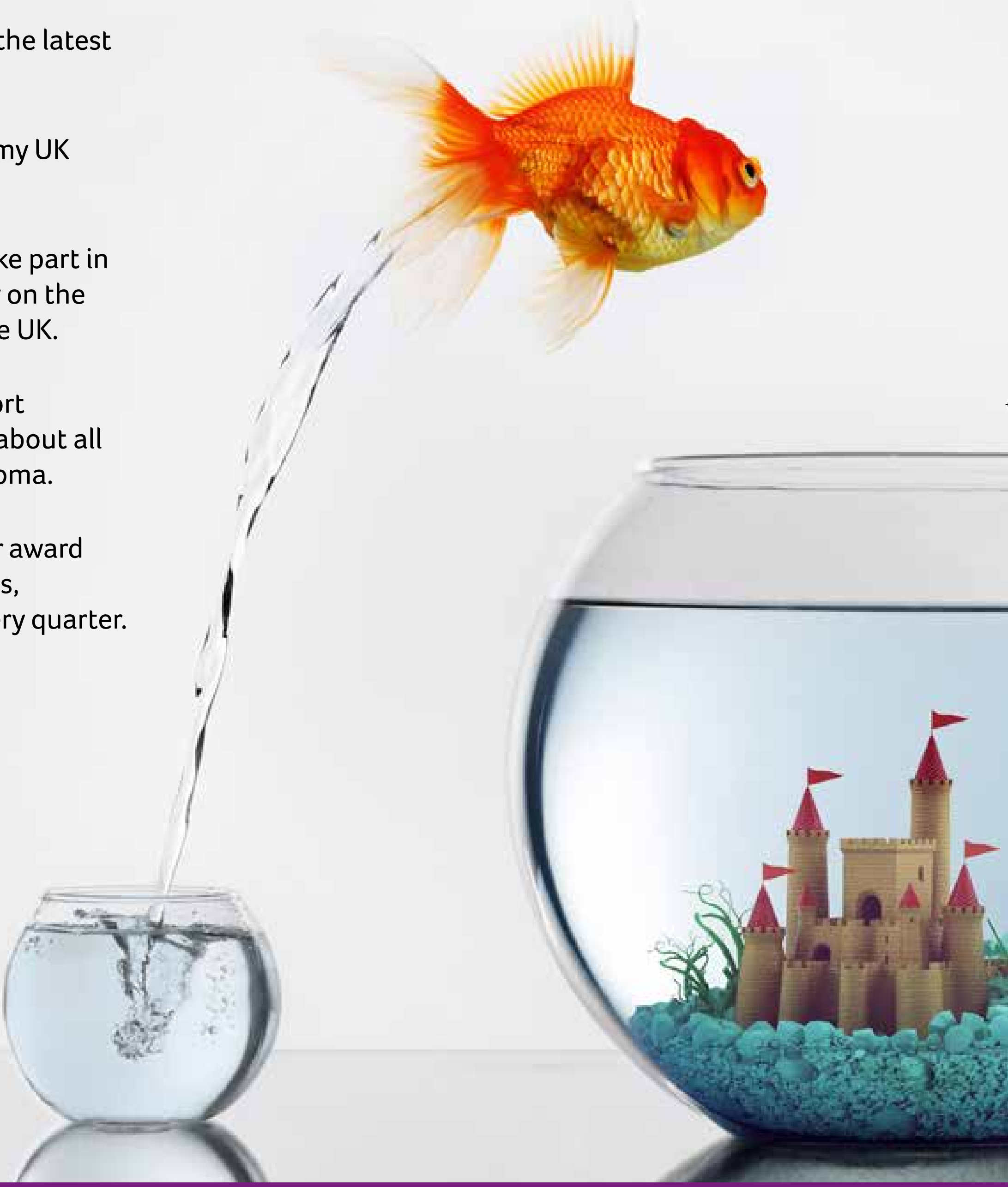

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Stoma on Board

Rachel Dodman

I live on a beautiful bright blue boat with my husband and 21–year–old son, Julian. People are often surprised when I tell them that the three of us live on the boat, but they don't know about Count Pooku. We wouldn't be able to live on the boat if we didn't have Count Pooku!

How did we get here?

Since birth, Julian's bowel has never worked properly. It didn't like emptying. As he grew, he became worse. He was always in pain – tummy aches, joint pain, back pain. He couldn't go to friends' houses, clubs or trips. School holidays were spent trying to get his medications to work better, generally in vain. He couldn't focus at school and looked pale, short and potbellied. Our life became his health.

When Julian was 11, doctors started talking about surgery. We met with a great doctor at the Evelina Children's Hospital to talk about having an ACE stoma. I'll never forget that appointment. Little tiny Julian in an enormous chair in this massive hospital, sat cross–legged, looking totally chilled. As the doctor started to explain what the surgery would entail – Julian confidently said: "I know, Mum and Dad already told me!".

In 2011 Count Pooku was created (named after Count Dooku from Star Wars)! Count Pooku is an ACE stoma. It enables a catheter to be inserted through a hole in the abdomen into the bowel. The contents of the bowel are washed out and go into the toilet. Julian uses an irrigation bag to hold a mixture of medicine and water which drips through the catheter and into his stoma. When the stoma is not being used, it has a stopper in and is covered with a dressing.

Post–surgery was difficult. Julian was in a lot of pain and was very down. He was in a hospital miles from home – too far for any visitors. The medical team seemed to expect him to recover quicker than he did, which made us both feel like we were doing something wrong. He was one of the older children on the ward and was allowed to watch Battle: LA in the hospital cinema. Not being treated like a little kid lifted his mood and oral morphine helped with the pain.

In the early days Julian needed us a lot but from a couple of months post–surgery he was independent. We offered advice and passed him things but the stoma has always been his.

He has had catheters stuck in the stoma, catheters stuck out of the stoma, leakage from the stoma and skin problems – which turned out to be an allergy to the adhesive.

In 2013 Julian was diagnosed with Ehlers–Danlos Syndrome (EDS).

Editor's note: regular readers may recall that in the spring 2020 edition of *Tidings* we published an article by Jane Green who is Chairperson for SEDS (Sussex Ehlers–Danlos Syndromes and Hypermobility Spectrum Disorder). To find out more about the condition please visit the **Colostomy UK** website, click the 'support' tab and then either download or view the relevant edition of *Tidings.*

EDS is a connective tissue disorder. Connective tissue makes up everything in the body. It explained the bowel problems, fatigue and joint pain. We understood why he had these problems and he felt listened to and acknowledged.

In early secondary school, he was off school more than he was there, but with the stoma and a diligent physio and OT, he was full time by his GCSE years.

Since school

Julian managed two years full time at college and two years at work before deciding to start his own business. The pandemic is making that a bit tricky, but he'll get there.

He is no longer a pale little lad. He's 2.34m (6' 2"), with long hair and a healthy glow!

I look back now at the times when Julian was little, and I don't fully believe how far he's come. I remember going to a weekend support group for children with bowel and bladder issues and talking to the mum of an older lad. Her son was a big, strong lad of about 17 and she was telling me about when he was ill. I distinctly remember thinking: "I'll never be able to say that. Julian isn't ill – this is just the way he is." I didn't think he would get any better or that he would ever have any energy, be able to hold down a full–time job or have a social life.

Now, I talk about "When Julian was ill"!

Life isn't perfect for Julian but his stoma doesn't hold him back. In his words: "My ACE is great, everyone should have one!" He has friends and a social life, and, most importantly, he is totally in control of his life and his health. It's only a few years ago that his health controlled us.

CONTINUED ON PAGE 37, COLUMN 1

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CONTINUED FROM PAGE 35, COLUMN 3

Back to the boat

Julian had a tough childhood. He was approaching adulthood and we knew that he'd leave home one day. We decided to do something memorable that we would all enjoy. In 2016 we sold the house and had a beautiful, bright blue, 60ft widebeam canal boat built.

We had a lot of concerns about how we would manage on the boat. Would we get too cold, what would we do if we had problems, would we manage in a small space? Count Pooku also gave us concerns. Boats are not connected to mains sewerage. The output from Julian's stoma (and the toilet roll) often blocked the house toilet – how would a boat toilet manage? How would we manage the rubbish? Where would he get his supplies delivered? Would the layout of the bathroom be suitable for Julian's equipment?

The boat was built with a macerator pump–out toilet. It was similar to a house toilet – ceramic, flushed with water and looked like a toilet. The waste went into a big tank on the boat and that was emptied every couple of weeks. It seemed like the perfect plan but the macerator blocked every time Julian even thought about using it! I spent many hours trying to unblock it.

We started off mooring the boat in a marina, so we had people around who knew what they were doing and somewhere onsite to empty the toilet tank. That was good, we learnt lots, but we didn't like being stuck in the marina. We preferred cruising and quiet moorings along the river.

After six months we left the marina and took up a mooring on the river (at the end of a cow field).

The pump–out toilet was no longer practical. It was a two to three hour trip to empty it! I never liked it because it blocked so much, so we tried a porta potty (like a camping toilet) to see if that was easier. That was better than the macerator toilet but filled up very quickly (which meant a three–mile round trip to empty it) and it still blocked, although less often than the pump–out toilet. Also, it was very low and Julian would get stiff legs when he used it. We're on the third toilet now and finally, it works well. It's composting toilet – which is impossible to block! It has no moving parts that can break and we don't have to travel anywhere to empty it. Julian says that the composting toilet is the best type of toilet for a stoma!

The other concerns we had were easier to solve. The rubbish just goes in a bin – there are a few dotted around for boaters. The supplies are delivered to a friend with a standard address.

The layout of the bathroom was a legitimate concern. Julian has to hang the irrigation bag somewhere high. This has caused him quite a few problems in the past, for example, where can he hang the bag? When we've been on holiday, he's ended up taping the bag to the wall, hanging it from a showerhead and tying a shower curtain into a loop so he could hang it from there! On one occasion I helped him and hung it on the hook on the back of the toilet door. That was fine until I closed the door, which pulled the catheter, attached to the stoma, tight and sent Julian dashing across the bathroom!

The boat actually has the best toilet/bathroom layout for Julian. The shower cubicle is right next to the toilet – so there is somewhere easy to hang the irrigation bag. The washing machine is in a cupboard in front of the toilet (washing machines in bathrooms is normal on a boat) and has a work surface above, which is perfect for Julian's supplies – and for him to put his laptop on while he's using his stoma (it can take an hour or two). It is the best laid out bathroom for Julian that he has ever used!

The biggest issue with a continent stoma on a boat is not Julian's, it's mine, and it's an issue I hadn't anticipated. In the house we had two bathrooms. Now we only have one. Julian's washouts take between one and two hours. My body seems to know when he is ensconced in the bathroom and uses that moment to tell me I need to go. There's only one solution to that – I have to go to the pub so I can use their loo! 🟩

Colostomy UK: focus on fundraising

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

Supporting Colostomy UK

We are a self–funding charity and rely on donations and grants to fund all our activities. Every £1 that you donate really helps. There are loads of ways you can support us. Visit https://www.colostomyuk.org/get-involved/fundraising/ for more details.

Give back 2020

On 1 December 2020 we took part in the international 'Give Back 2020' campaign which encouraged individuals to give back to charities that had supported people through the pandemic. We used the day to showcase our Active Ostomates at home programme and ran several taster sessions on Facebook live including chair yoga, art, mindfulness and meditation, and dance.

We also managed to raise an impressive **£2,318,** so thank you to everyone who donated and joined in the activities.

Could you raise funds on your birthday too?

Setting up a birthday fundraiser on Facebook is an easy and straightforward way to raise funds for **Colostomy UK.** Encourage your friends, family, and followers to donate and help us continue to make a difference for people with stomas.

For more details visit: **facebook.com/fund/colostomyuk**

In the bag!

If you're planning a clear out, you can donate your unwanted clothes, paired shoes, linen, bedding, towels and curtains to iCollectClothes, and at the same time generate much needed funds for **Colostomy UK!** They can also collect accessories (bags, belts, hats, scarves), books, DVDs, CDs, soft toys, electronics and small domestic appliances.

If you live in Greater London, the West Midlands or Merseyside you can book a collection online at: **icollectclothes.co.uk/donate/colostomy-uk** or by calling: **0344 879 4417.**

For all other areas give them a call on and they will be able to advise when they will be collecting near you.

Hitting the ground running in 202

We have had a brilliant start to 2021 with supporters taking on some
Some have already finished, and others would really benefit from you

Lisa's 1,609km walk

Lisa Gordon is aiming to walk 1,609km (1,000miles) to raise funds for **Colostomy UK** this year. She explains why in her own words.

> *"I have Crohn's disease and have had an ileostomy since 2013. It has given me so much of my life back although I still suffer almost daily with symptoms such as fatigue, stiffness and joint pain, and having an ostomy has given me extra worries such as leaks, sore skin and blockages.* ***Colostomy UK*** *have been a huge support, especially their Facebook [support] group. As I desperately want to raise money for this worthwhile charity and I'm unsure when I'll be able to hold my fundraiser I have set myself a challenge of walking 1,609km (1,000miles) in 2021.*
>
> *"I'll be honest I'm not much of a walker (I'm quite lazy), but this challenge gives me the push I need to get out there and get fit (well, attempt to) and improve my mental health while raising money for such a good cause"*

If you'd like to support Lisa by donating to her fundraising page you can do at the following link:
justgiving.com/fundraising/lisa-gordon17

You can also follow Lisa's journey on Facebook:
facebook.com/walkforcolostomyuk

Robert runs the world

In December Robert Gale set himself the challenge of running 39km (24miles) in 24 hours. He then decided to see in the new year by running a mile for each of the worlds 38 time zones! He started at 10:00am on New Year's Eve and finished at midday on New Year's Day, and despite struggling to walk for a couple of days afterwards managed to raise a fantastic **£920.**

Doug's 5K Challenge

Four years ago, Douglas Ball had stoma surgery due to complications with diverticulitis. This January he decided to shake off the winter blues by running five kilometres a day, every day of the month, to support us. At the time of writing not only is he more than meeting that target but he has also raised over **£300.**

21

great challenges and fundraising activities to support **Colostomy UK.**
r support!

Sue's 70th Birthay

Long term **Colostomy UK** volunteer Sue Hatton celebrated her 70th birthday by asking friends and family to donate to her fundraising page. She may have had to celebrate her 70th birthday in lockdown, but that did not stop her raising a fantastic **£1,500** for **Colostomy UK!**

Sue has been associated with our charity for two decades now, having had bowel cancer 24 years ago leading to the formation of a stoma. Many will know her as a friendly voice who often answers our Stoma helpline (0800 328 4257), offering fantastic experience–based advice to those in need. You can read more about Sue's 'stoma story' in the last edition of *Tidings.*

Emily's awareness day

On 27 January, Emily and 50 friends wore a stoma bag filled with porridge for the day to try to gain a small glimpse of what ostomates experience every day. The idea was to raise awareness while raising funds for **Colostomy UK** at the same time.

Emily decided to do this in memory of her nan who had a stoma due to bowel cancer. When the cancer returned Emily helped to care for her nan and the experience led her to undertake an access course to go to university. She is now in her second year of an adult nursing degree. Emily said: "Throughout my work and [degree] placement I have seen patients and their families deal with their new stoma and have been lucky enough to have been a part of that journey. This fundraiser was in memory of my nan but is also to make sure that people get the support they need to help them through the mental health and physical effects of [having a stoma]." At the time of writing Emily has already raised over **£300.** If you'd like to make a donation to her fundraising page you can still do so here:

justgiving.com/fundraising/emily-dunstan

Putting the FUN back in FUNdraising

Doing something amazing is about the people that you help, not the challenge you take on. You don't need to climb Everest to fundraise for **Colostomy UK.** You can bake a cake, hold a (virtual) tea party, or organise a sponsored walk, and have a great time while doing it!

A successful event doesn't need to raise huge amounts of money either. Our fundraising pack is full of ideas to help get you started. If you would like a copy just call us on **0118 939 1537** or e–mail **fundraising@ColostomyUK.org**

Thank you!

We want your stamps!

WANTED

POSTAGE STAMPS

- STAMPS TO BE CUT / TORN FROM RECENT MAIL
- BRITISH AND FOREIGN STAMPS – NO NEED TO SEPARATE
- NO MORE THEN 1CM OF ENVELOPE LEFT AROUND EACH STAMP
- DO NOT TRIM STAMPS TOO CLOSE SO THAT PERFORATIONS ARE DAMAGED

Send your stamps to -

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

You can now donate your used and unwanted stamps to **Colostomy UK**. Please see the image above for details.

Colostomy
UK

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

If you're a UK tax payer, tick the Gift Aid box on the donation form (right) 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

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

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

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 ☐ Telephone. Please tick if you would like a receipt ☐

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):

- ☐ Tidings the quarterly **Colostomy UK** support magazine
- ☐ 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 general data protection regulation (EU) 2016/679. 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.)

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 ☐ 25th of the month, 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: **C.A. Ltd** Account No: **88781909** Sort code: **60-17-21**

Name: (IN CAPITALS)

Signed: Date: / / 2021

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.

T61

Signed: Date: / / 2021

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

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)*

Address

Postcode

Donation Details

I would like to make a regular donation of £

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

01 / ☐☐ / ☐☐☐☐ *or*
15 / ☐☐ / ☐☐☐☐

Gift Aid Declaration

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*

This guarantee should be detached and retained by the Payer

The Direct Debit Guarantee

T61

- 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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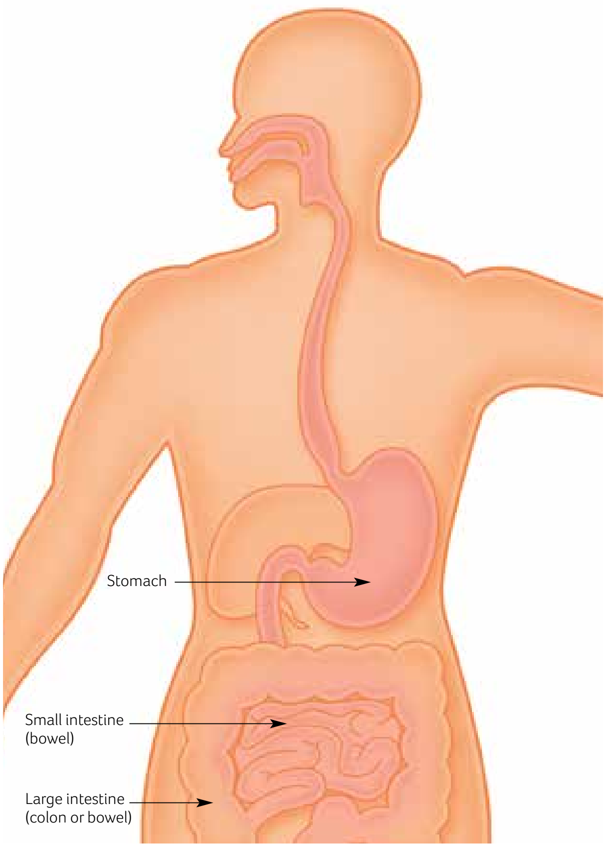
Retained rectal stump and rectal discharge

Jennie Burch
Head of Gastrointestinal Nurse Education, Academic Institute, St Mark's Hospital

If there is a problem with the gut, the treatment is often medication, but for some people the treatment is surgery. The formation of a colostomy can be necessary for a number of reasons and for some people the surgery might result in the rectum being left inside. Three common reasons for having a colostomy formed are a cancer in the colon or rectum, Crohn's disease or diverticular disease. Surgery for any of these diseases might involve the removal the rectum (back passage), anal canal and anus; in which case there will not be any rectum left. However, in some operations such as one called a Hartmann's procedure, the rectum is left.

Hartmann's procedure

If we consider the anatomy of the gut, it helps to explain what this means. The gastrointestinal tract is a passage that starts at the mouth and ends at the anus. Above the anus is the back passage (rectum) and this is the place that bowel motions are stored before they are passed into the toilet. A retained rectal stump is simply any part of the rectum that is left inside when a colostomy is formed. For some people the rectum might be removed at a later time and for others the rectum might be re–joined at a future operation. However, for some the rectal stump is left in situ (left inside) and can be termed a retained rectal stump.



The gastrointestinal tract

Thinking back to our knowledge of how the gut works, helps with understanding why certain things might occur, such as discharge from the back passage following stoma surgery. The role of the gut is complicated, but its main functions are to ingest, digest, absorb and eliminate. Thus we ingest food by eating and drinking. Digestion occurs in various parts of the gut such

CONTINUED ON PAGE 45, COLUMN 1

Colostomy UK

R♻cycle and Raise Funds

We've teamed up with 'iCollectClothes' to offer a hassle-free way of donating items you no longer want. They will collect clothing, shoes, linen, bedding, towels, curtains, accessories (bags, belts, hats, scarves), books, DVDs, CDs, soft toys, electronics and small domestic appliances and convert them into a donation for Colostomy UK.

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

If you live in Greater London, the West Midlands or Merseyside you can book a collection. For all other areas give them a call and they will be able to advise when they will be collecting near you. Book your collection by calling **0344 879 4417** or book online at **icollectclothes.co.uk/donate/colostomy-uk**

CONTINUED FROM PAGE 43, COLUMN 2

as the stomach. Then the nutrients and fluids from the diet are absorbed to provide us with energy. Finally, and most important to this article is elimination. Prior to surgery, elimination would be the passage of faeces (bowel motion) from the back passage. To help the food and bowel motion move smoothly through the body, the gut surfaces are lubricated. The lubrication in the mouth is saliva and this keeps the mouth moist. Within the rectum the lubrication is mucus, which comes through the inner surfaces of the rectum. This means that when there is a retained rectal stump although there is no bowel motion needing to be lubricated, mucus is still made.

It is likely that much of this mucus will be reabsorbed back into the body, but some may be passed from the anus, albeit not everyone with a retained rectal stump reports this. In the initial period after a colostomy is formed there may be more mucus passed than as time passes. It appears for most people that the number of times that mucus is passed decreases over time. There is often only a small amount of mucus passed. The mucus itself is often of a jelly–like consistency and can be stained brown and can be smelly. This is normal. What's not normal is for the mucus to contain blood. Passage of blood should be reported to a healthcare professional such as your surgeon or GP immediately, as tests may be required to check out why there is bleeding. It is likely that the blood does not mean anything, but it should be checked out the first time bleeding is noticed and if there is more than a tiny trace of blood seen.

Understandably, mucus can cause concerns for ostomates affected by it. Some people worry that the mucus is in fact a bowel motion. Others fear they cannot control the mucus leaking out or are worried about the odour associated with it. It can be difficult to know what to do about mucus. Many people find that simply sitting on the toilet enables the mucus to be passed. If there is inadvertent passage of mucus without control or knowledge, a small pad might be of use. You could also try a non–woven swab, which some ostomates prefer, as these are less bulky than pads. Alternatively, sitting on the toilet regularly and trying to pass the mucus can prevent it being passed at other times. If there are problems with mucus that cannot be resolved simply, it can be useful to speak to your colorectal consultant, your GP or your stoma care nurse; though some might not be familiar with the topic.

So in conclusion, some people with a colostomy might also have a retained rectum. In many cases this does not cause a problem. However, for a few people the mucus that the lining of the gut makes can lead to this passing out of the anus. Mucus discharge does tend to reduce over time but when it is a problem there are ways to address it, such as sitting on the toilet. Additionally a healthcare professional may be able to assist. Finally, if bleeding is noticed it is important that this is reported to a healthcare professional such as the GP. 🟩

Want to read more about this topic?

Then visit our website and download a free copy of our booklet or if you would like it in hardcopy then call our admin line: **0118 939 1537** or email: **Info@ColostomyUK.org** to request one.

A RADAR key costs just **£4.50** and opens the door to over 9,000 accessible toilets in the UK. Toilets fitted with the National Key Scheme locks are found all over the country, in shopping centres, pubs, cafes, department stores and many other locations.

You can also get a photo ID card from **Colostomy UK** for **£6.50.** Endorsed by Disability Rights UK and displaying their logo, this can be helpful if you need to use accessible facilities urgently, particularly if they aren't part of the National Key Scheme.

To order a RADAR key and/or photo ID card please complete the form to the right. You can also place your order with a credit or debit card online at: **https://www.colostomyuk.org/information/radarkey/** or by calling us on: **0118 939 1537.**

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

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

To obtain a **key or a photo identity card** please **complete the form and declaration below.** Make your **cheque payable** to **Colostomy UK.** Return all required items to:
Colostomy UK, Enterprise House, 95 London Street,
Reading, Berkshire, RG1 4QA

(If you have any queries or would like to pay by credit card, please contact **Colostomy UK** office:
Telephone: **0118 939 1537** or Email: **info@ColostomyUK.org)**

National Key Scheme – Key and photo ID card purchase

Title:

Name:

Address:

Postcode:

Tel:

Email:

Please **tick** as appropriate:

☐ I would like to receive a **key £4.50** (including postage and packing).

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

NOTE: For ID card orders don't forget to a include a copy of your prescription/recent delivery note as proof of eligibility. Cheques should be made payable to **Colostomy UK.**

For payment by credit card, send your documents in the post with a contact telephone number, we will then call you to take a card payment when received.

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

Signature of self or carer: Date: / /2021 T61

Halfx3 15v00r00 Photo ID Application | Date of Publication: December 2020 | Copyright ©2018–2021 Colostomy UK | Registered charity no. 1113471

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

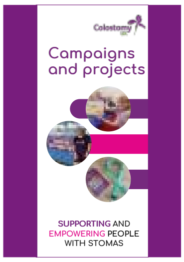
Colostomy UK literature range

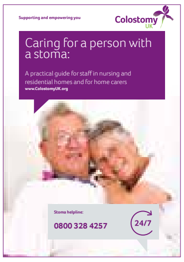
Have you seen our extensive range of support literature? Suitable for ostomates, family members, friends, carers and healthcare professionals.

To order your complimentary copies contact us by:

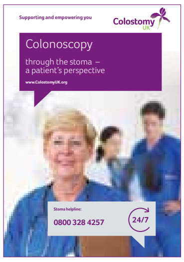
adminline:	eMail:	website:
0118 939 1537	info@ColostomyUK.org	ColostomyUK.org/information


Active Ostomates Sport and Fitness after stoma surgery


Campaigns & Projects Flyer


Caring for a person with a stoma


Caring for a person with a stoma and dementia


Colonoscopy through the stoma

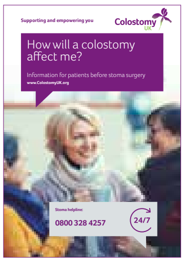

Fundraising Pack

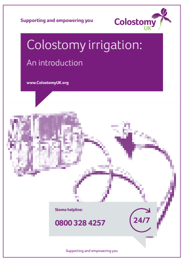

Healthy Eating

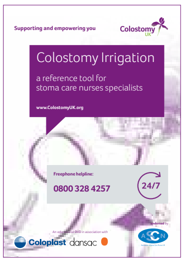

call the stoma helpline for:
emotional support, experience based advice and guidance from a volunteer.
0800 328 4257
24 hours a day and completely free.

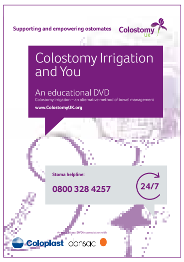
call the adminline for:
information packs, ID cards, radar keys, travel certificates and literature.
0118 939 1537
if we're not in, just leave a message.

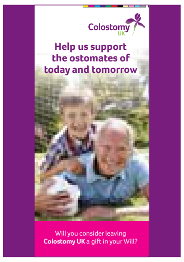
Helpline Cards

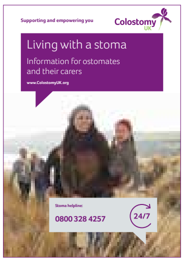

How will a stoma affect me?

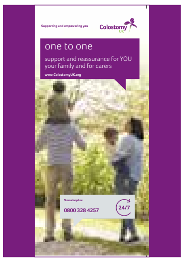

Irrigation Booklet


Irrigation DVD (nurses)


Irrigation DVD (patients)

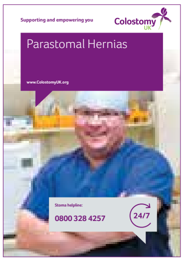

Legacy Flyer


Living with a stoma


One to One (join us) Flyer


Ovarian Cancer and stomas

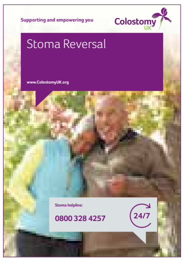

Pain & Discomfort

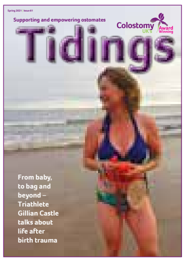

Parastomal Hernias

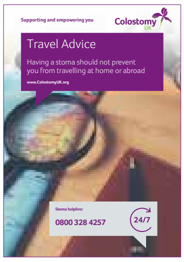

Rectal Discharge


Sam has a stoma (colouring book)


Stoma friendly toilet guideline and stickers

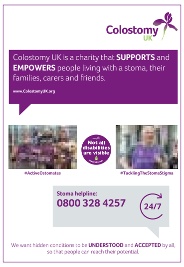

Stoma Reversal


Tidings Magazine


Travel Advice


Travel Certificate


Tri-Charity Leaflet


Welcome Pack

An ostomy bag… could it be verse?

John Hunter

My name is John Hunter and I live in Birmingham. I retired from working in local government in March 2018 at the age of 65. My intention was to spend time travelling and pursuing my hobbies, of which writing is a major one.

Both my parents had bowel cancer and, as a precaution, I underwent a regular test every two years. Therefore, it was really no surprise when the test came back positive in September 2019. Later that month I had a colonoscopy examination, and a tumour was found in my bowel.

I was prescribed a course of chemotherapy and radiotherapy, followed by surgery. On 24 March 2020 I had a laparoscopic anterior resection and loop ileostomy and became an ostomate. I believe I was the last patient to receive such a treatment at the Queen Elizabeth Hospital in Birmingham before this sort of thing was suspended because of the first Covid–19 lockdown. Luckily for me, when the tumour was examined no cancer was found remaining in the bowel.

I have been living with a bag since then, eagerly awaiting news of when I can have a reversal. I continue to write and in 2019, under the pseudonym John Wright, I had a book of humorous poems about travelling by bus published. The book is entitled *Riding the Top Deck.* The poems below are written in a similarly light and humorous way. They address three key issues about my dealing with cancer.

Colonoscopy: The first poem is about my colonoscopy. My hope is that it will encourage people to attend for a procedure if called upon to do so.

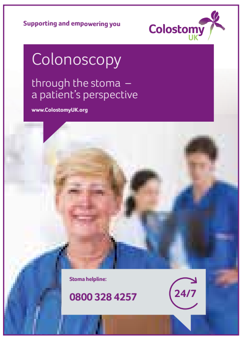
Bag Change: These three short poems deal jokingly with the experience of bag changing and how, in my case, this varies according to my mood!

Stoma–Reversal Surgery: The last poem is about stoma–reversal surgery. The form of the poem is known, somewhat ironically, as a 'reverse' poem. I was quite pleased to discover this form as I think it is a good complement to the content. The poem when read normally from top to bottom paints a rather bleak picture, but when read in reverse from the bottom to the top puts a much more positive spin on the situation.

Would you like more information about colonoscopies?

Request a copy of our brochure by email: **info@ColostomyUK.org** or download it from our website: **ColostomyUK.org/information/a-z-list/**

Don't forget, you can also call our 24–hour stoma helpline: **0800 328 4257** to speak to a volunteer who has experienced the procedure.



Supporting and empowering you

Colostomy UK

Colonoscopy

through the stoma –
a patient's perspective

www.ColostomyUK.org

Stoma helpline:
0800 328 4257

24/7

Colonoscopy

Cancer has a certain commonality
Among the peoples of the Queen's UK.
So when you get the call to test,
To go and get it really is best.

So I went for my colonoscopy,
But did not do so confidently,
For refusing was not really optional
And a bad result, highly probable.

As the camera took up occupancy,
I had a certain preoccupancy,
And watched it all on their smart–TV:
A feature film involving me!

We examined the pictures ominously,
But the whole event went profitably,
For the tumour showed up prominently –
And explained my late, incontinency.

I was at first disconsolate,
And railed quite loudly against my fate.
The Consultant allayed my greatest fears,
And wiped away my flowing tears.

"We'll beat your tumour. I'll cut it out."
He ventured up quite breezily,
"Chemo and Radiotherapy,
Should both go down quite easily."

His confidence in those therapies
And his good cheer, ringing merrily,
Helped disperse the clouds of obstinacy
That held me in dark despondency.

So if – and somewhat unluckily –
You need a colonoscopy,
Don't behave abominably
Accept the invite, honourably.

The day before you're due to go
To attend that dreaded check–up,
Just have a drink to help you cope,
And raise a toast of "Bottoms up!"

CONTINUED ON PAGE 49, COLUMN 1

Win up to £25,000 with Unity

50p From every £1 goes to Colostomy UK

Unity is a lottery with a difference. We receive income directly from the number of lottery players we recruit, so we need your support. For every £1 entry – 50p comes directly to **Colostomy UK**.

How it works

For just £1 per week you will be allocated a six digit **Unity** lottery number. You can purchase more than one entry if you wish. Every Saturday, the lucky winners are selected at random and the prize cheques posted directly to you, so there is no need for you to claim. You must be 16 or over to enter. Winners have to match 3, 4, 5 or all 6 digits of the winning number in the correct place in the sequence.

How to join – three easy steps

Step one – Complete your personal details - so that we can contact you if you win.

Step two – Select the number of **Unity** lottery entries you wish to purchase per week and how often you wish to play.

Step three – Complete the direct debit instruction or enclose a cheque. Detach the form, put it into an envelope and return to **Unity** to the address shown on the right panel. **Unity** will notify you of your **Unity** lottery number.

If you have any queries please call our hotline on

0370 050 9240

Results & Rules can be checked by visiting

www.unitylottery.co.uk

Or by phoning the Unity winners hotline

0370 055 2291

Calls cost no more than calls to geographic numbers 01 or 02.
You must be 16 or over to enter.

Prizes **£25,000** 6 digits | **£1,000** 5 digits | **£25** 4 digits | **5 Prize Entries in the next draw** 3 digits

1. Your details (please print in block capitals)

Title: First Name:

Surname:

Address:

Postcode:

Tel: Mobile:

D.O.B.: If you would like to receive correspondence via email, please tick here ☐

Email:

☐ If you do not wish your name to be publicised if you win, please tick here

2. Payment Frequency

How many entries would you like each week? ☐

x

How often do you want to pay?

(please tick payment frequency and write amount in box)

☐	Monthly	£4.34 Direct Debit only
☐	Every 13 wks	£13
☐	Every 26 wks	£26
☐	Every 52 wks	£52

→ ☐

=

Total Payable ☐

3. Select your Payment method

☐ **Payment by Cheque** ☐ I enclose a Cheque made payable to Unity (minimum payment £13)

☐ **Direct Debit** Please fill in the form and return to **Unity**
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)

Branch Sort Code: ☐☐ ☐☐ ☐☐

Bank/Building Society account number ☐☐☐☐☐☐☐☐☐☐

Banks and Building Societies may not accept Direct Debit instructions for some types of accounts.

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

Service User Number 4 2 1 1 0 2

Reference:

Instruction to your Bank or Building Society
Please pay **Unity** 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 **Unity** and, if so, details will be passed electronically to my Bank/Building Society.

Signature: Date:

4. Your consent to Play (I confirm I am 16 or over and resident of GB)

Signature: Date:

☐ Occasionally, **Colostomy UK** may send you samples and information that may be of interest to you. We do not pass on your details but may use them to keep you informed of what else is available. If you would prefer not to receive these, please tick the box.

Detach the form, put it into a stamped envelope and return to **Unity** at the address shown on the right. They will notify you of your **Unity** lottery number.

Post this form in a stamped envelope to:

The Unity Lottery
Furness Gate
Peter Green Way
Furness Business Park
BARROW-IN-FURNESS
LA14 2PE

For office use only:

T61

The Unity Lottery, Furness Gate, Peter Green Way, Furness Business ParkBarrow-in-Furness | T: 0370 050 9240 | E: info@unitylottery.co.uk
Unity is operated by Sterling Management Centre Ltd, registered as an External Lottery Manager by the Gambling Commission under the Gambling Act 2005 – www.gamblingcommission.gov.uk

The promoter of this Unity lottery is Colostomy UK, Enterprise House, 95 London Street, Reading, RG1 4QA | Registered with Reading Borough Council Registration number: LOT000141

CONTINUED FROM PAGE 47, COLUMN 2

Bag Change

My approach to changing the bag alters depending on my mood.

Cautious

One thing I never, ever, do
Is choose to underestimate,
How long it takes to change the bag:
For I am a cautious ostomate.

I set aside an hour or two,
(You cannot rush these things,
Something might go wrong you see,
You know what rushing brings.)

I gather all the tools I need,
The bags, the wipes, the tapes and sprays,
And cut the template carefully,
To guarantee, once stuck, it stays.

And when complete, I tidy up,
Breathe deep, and proudly contemplate,
The job I've done, then smile with joy:
That I am a cautious ostomate.

Casual and laid back

When I'm feeling casual,
I really don't give a damn,
If it leaks and burns my skin,
That's just the way I am.

I'll change it when I want to,
Or 'guess', the time is right,
And wash the bedclothes in the morn
– After a bag–leak night.

And when my skin is stinging
And the bag begins to itch,
I'll scratch it like a monkey
Rather than make a switch.

Heigh–ho, for being laid–back
It is the way to go,
No cares, no worries in the world.
Hold on! I've got to go…

Ignorant or thoughtless

When I don't *think,* I fail to note
The simple causal chain
That changing the bag just after food,
Creates a poo–filled rain.

The stoma gets quite restless,
And spits and squirts and blows,
Sending liquid faeces
Down upon my clothes.

I'm sure it did this last night,
And at this same time too,
You ask me what the reason is –
I haven't got a clue!

A 'reverse' poem.

Stoma Reversal Surgery

I will never get my stoma reversal surgery.
And I refuse to believe that
We can kill the Covid virus.
I realise this may be a shock but
"The vaccination will cure us all"
Is a lie, and
"The Hospitals cannot cope"
In ten years' time I will say
I have my priorities straight because
Death
Is more important than
Life.
I tell you this:
Once upon a time
I would have been cured
But this will not be true in the future
Medical science fails all the time
Experts tell me
I should give up, make a will, go home
and die.
I do not believe that
I will be fully restored to health.
In the future,
Millions will die from this rampant virus.
No longer can it be said that
Science can find a cure for all.
It will be evident that
Not everyone will survive the virus.
It is foolish to presume that
Although I have been waiting so long,
one day I will be called.

Now read it again from the bottom to the top

Stoma Reversal Surgery

Although I have been waiting so long,
one day I will be called.
It is foolish to presume that
Not everyone will survive the virus.
It will be evident that
Science can find a cure for all.
No longer can it be said that
Millions will die from this rampant virus.
In the future,
I will be fully restored to health
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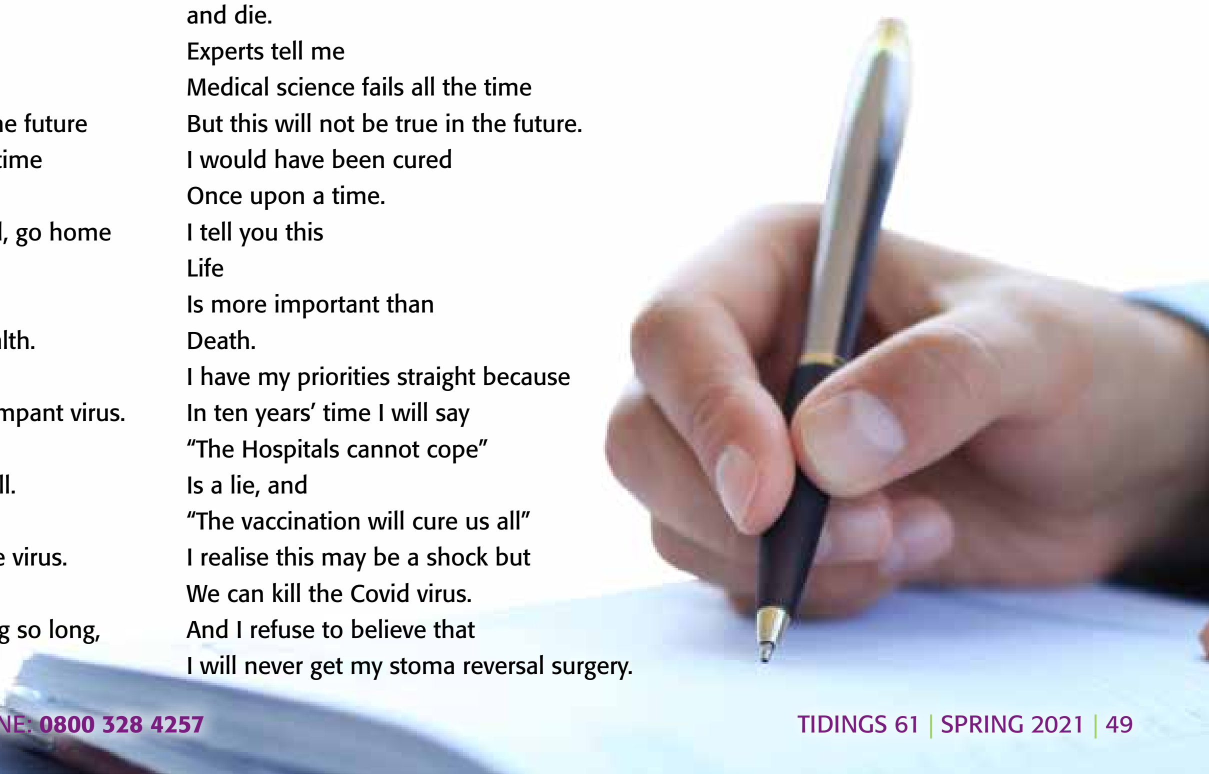
I would have been cured
Once upon a time.
I tell you this
Life
Is more important than
Death.
I have my priorities straight because
In ten years' time I will say
"The Hospitals cannot cope"
Is a lie, and
"The vaccination will cure us all"
I realise this may be a shock but
We can kill the Covid virus.
And I refuse to believe that
I will never get my stoma reversal surgery.

Would you like to know more about reversal surgery?

Request a copy of our brochure by email:
info@ColostomyUK.org
or download it from our website:
ColostomyUK.org/information/a-z-list/

Don't forget, you can also call our 24–hour Stoma helpline:
0800 328 4257 and we can arrange for you to speak to a volunteer who has had a reversal.



Your letters and e–mails

Editor's note: Despite the festive season, it was great that people still found the time to drop me a line. It was also heart warming to receive so many kind comments about the magazine. They certainly led to plenty of smiles from the editorial team and everyone else at Colostomy UK. **Please keep those letters and e–mails coming!**

Dear Editor

I have enjoyed all the articles and life changing stories that have appeared in your *Tidings* magazine over the years. However, I cannot remember being so moved as I was on reading the story of Dave Thraves and his journey to receiving a stoma.

Having survived a horrendous accident, his courage and determination to regain control of his life and independence is inspirational and not once did I feel that he was looking for pity nor praise. He coped with everything that the accident threw at him.

That fateful day in 1992 when he had the terrible accident that was to change his life forever was the beginning of a long painful and personally distressing time.

The fact that he had to submit to a bowel care routine for over an hour by nursing staff and later by care home staff must have been difficult to accept, especially as it resulted in other problems around the bowel.

We have all arrived at receiving a stoma in many ways, but I can't think that many of us would have suffered for 23 years before such an answer would bring such relief.

I read on – and began to relax when by further reading I was able to learn that Dave's life has been greatly changed by his stoma.

Soon, I hope, he will be able to return to the duties he loves, giving talks at schools, colleges, hospitals, and universities. I do hope that you will continue to ask Dave to write updates for us – his story shows that you can get through anything with courage and determination.

His little "friend and companion" Ronnie also has been through the "operation bit" – I hope both of them continue to see a bright future.

JRD

Dear Editor

Having used colostomy dressings over 40 years now, I tried a Coloplast SenSure one–piece ostomy bag* (donated to me by relatives of a recently deceased dear friend and found in their belongings). I found it excellent to remove the solids over two days – with a drop of baby oil sprayed in the bag before applying it to my skin. I also like the variation in adhesives between this and my usual Braun Softina, (it gives my skin a change of chemicals or something).

My other main introduction is the use of a very temporary but absolutely practical now (for a few years) thin plastic sandwich bag about 152mm square and Vaseline and toilet tissue – small pad. I smear Vaseline round the stoma and lightly press the tissue pad with about 25mm–50mm around as adhesive border. Then a square lined smear of Vaseline along the area where the thin plastic can be pressed onto the skin and with my neatly fitted knickers everything stays remarkably in place and can be briefly released to allow solids to drop into the WC before replacing the pad, pressing on the plastic and forgetting all about it until another emptying is felt close.

I do not have soft motions, more like animal droppings, maybe the apple a day helps this situation!

Mrs B W

*Mrs B W is referring to a drainable bag.

Dear Editor

My father Brian Saul was a colostomate for some 20 years and looked forward to receiving your magazine and often pointed out to me interesting articles to help my understanding of his condition. He was a great advocate of colostomy irrigation for the freedom and confidence it gave him to continue to holiday abroad and pursue his hobbies.

Sadly, in March this year, my Dad passed away at the age of 83 and I was left with the task of disposing of a mountain of unused colostomy supplies. Due to Covid–19 this proved a difficult task and I was anxious that they should not end up in a landfill site. I was put in touch with a fantastic charity called 'Jacob's Well' that forward unused medical supplies to Africa, where they are in desperately short supply (they can even be opened boxes of supplies). Colostomates in countries such as Burkina Faso sometimes have to resort to using crisp packets or carrier bags as they cannot always get hold of colostomy bags! I sent 10kgs by courier at a very reasonable price to Jacob's Well's headquarters in Yorkshire and had the satisfaction of knowing that these would be put to good use.

Here is the address for your readers:

Jacob's Well Appeal, Jacob's Well Yard,
Swinemoor Lane, Beverley, East Yorkshire,
HU17 OJX

They also have a website which tells you about the work they do.

Kind regards
Alison Kulbacki,
Preston

Dear *Tidings*

You have been my guiding light, comfort and help for five years. I always read you cover to cover and have read many interesting stories of people's experience with bowel cancer and thought perhaps mine was unusual and might be worth others reading.

My name is Valerie. I am 85 years old. Five years ago, we decided to take our caravan and go on holiday. Unusually, I had been constipated for several days when we arrived. After a week still constipated, I visited a local GP who gave me sachets of laxative and said come back in a week if nothing changes. The following Thursday, still nothing. I was eating nothing and a bit uncomfortable, though nothing drastic. That night the pain started. I sat up all night. At 5:00am I decided to wake my husband, who rang for an ambulance. They came quickly and took me to the John Radcliffe.

The treatment there was beyond excellent. I didn't have to wait in A&E and was quickly up to a ward. I had tests over the next couple of days and much poking around inside. I had an injection for the blockage but this didn't work. Then the surgeons called on me and asked if I had blood in my poo, pain or diarrhoea – 'no never' – I said. Well, they said: "from your blood tests etc. we are sure you have bowel cancer." It was a fait accompli – no time to fuss or worry. On the Sunday morning, a great robed and masked figure appeared at the door and said: "Off we go to theatre." I was given an injection and knew no more about it. When I came round I was in pain but nothing too dreadful and it was quickly put right. Two wonderful surgeons operated on me for seven hours. I had a Hartmann's and of course, a stoma – I called it Bilbo and have read in my Bible, *Tidings,* that someone else called theirs Bilbo too – human minds are so alike.

I was so grateful to the surgeons and was up walking the following day – no complications and so I was sent home a few days later. I had just eight days in hospital altogether. The district nurse came and took out the clips and stitches all painlessly and the stoma nurse at the John Radcliffe did a first class job in showing me the stoma bag change and I had no problems doing it.

I would say to anyone who finds they have bowel cancer, maybe I was lucky to get through it all so easily, or maybe it's never as bad as we expect! I do have two hernias which I am told at my age are too tricky to operate on, but I manage well and am still glad to be alive, thanks to surgery.

Valerie Thomas

Dear *Tidings*

How green is your bag?

Having recently watched the excellent BBC documentary about the history of landfill sites (The Secret Life of Landfill: A Rubbish History) it made me wonder about the bags of full of output that I throw into my bin every day! Like nappies, I'm reliably informed that, as composite materials, containing medical waste, they are extremely difficult to recycle and so almost all end up in landfill. But the question is, will they ever decompose?

Someone once told me that nappies in landfill will take between 200 and 500 years to fully decompose and whilst, as a family we try to be recycling conscious, I can't help wondering what all the suppliers of ostomy bags/pouches are doing to make their products eco–friendly, because my rubbish bin sure does fill up with them each fortnight.

When I posted something on Twitter to this effect, I was encouraged by the response from fellow ostomates and therefore this letter is a sort of call for action and perhaps others with more experience in these matters might start to think and shout about what we are throwing into bins every day.

Someone suggested that one option was to use potato starch bags and someone else told me that they had swapped oxo–biodegradable dog poo bags for the complimentary 'hygienic and odourised disposal bags' that her supplier sent her each month. However, it's what's going in the bags that will remain in the ground and not decompose, for the longest time.

We are not sure if anyone has the magic answer however we did start asking some of the suppliers, that are keen to get our regular business, if they could provide us with a copy of their company's environmental policy or if they had a research and development unit that might be focusing a part of their time on green issues. Sadly, we can't say that our inboxes have been overflowing with replies!

What next? – we are keen to see what others might think about this subject and to learn about the moves people might be making (or thinking about making) to help nudge the various companies that produce these products to think outside the bin!

Do Tweet us at @HowGreenisYour1 or send a letter to *Tidings.*

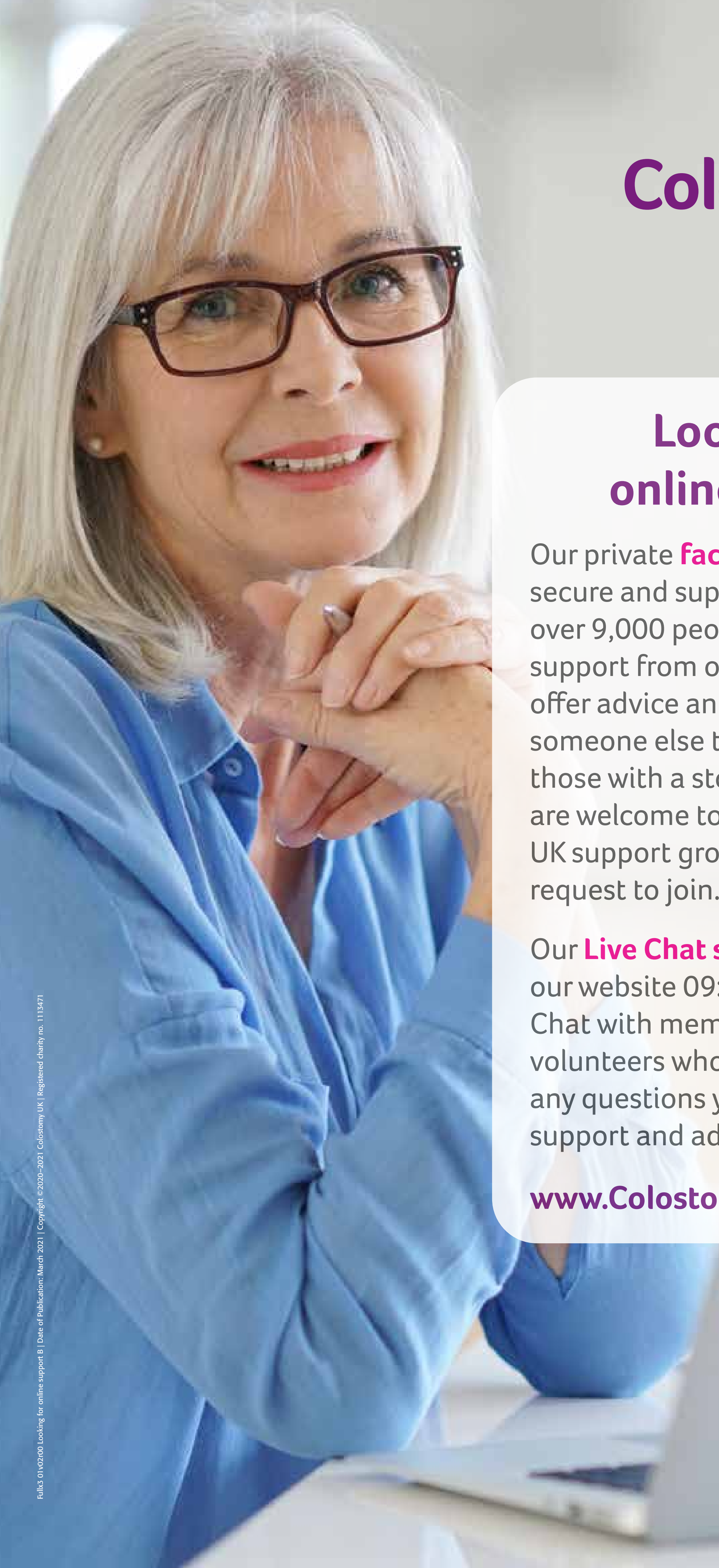
Yours
Matthew Wing and Emma Joy

We look forward to hearing from you, our readers:

Send an e–mail to: **info@ColostomyUK.org**

Write a letter to: **The Editor, Colostomy UK,**
Enterprise House, 95 London Street,
Reading, RG1 4QA

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



Colostomy UK

Looking for online support?

Our private **facebook group** is a secure and supportive community of over 9,000 people where you can find support from others with a stoma, offer advice and, if you need it, just find someone else to talk to. It's not just for those with a stoma; friends and family are welcome too. Search for 'Colostomy UK support group' on Facebook and request to join.

Our **Live Chat support** is available on our website 09:00–17:00 on weekdays. Chat with members of our team and volunteers who will be able to answer any questions you have and offer support and advice.

www.ColostomyUK.org

Fullx3 01v02r00 Looking for online support B | Date of Publication: March 2021 | Copyright ©2020–2021 Colostomy UK | Registered charity no. 1113471

My crusade to raise awareness of hidden conditions

Jessica Logan

Back in the spring of 2019 we featured a woman called Jessica and her struggles (mental and physical) with IBD. It was a story that divided the *Tidings'* editorial board. Everyone knew it was important, but some were concerned about how readers might react to the cover picture we planned to use. This showed Jessica in just her underwear, with her body daubed in carefully selected words each of which described some of what she had been through. It was wondered whether a less provocative image was more in keeping with our magazine.

Having worked with Jessica writing the piece, I knew that the photograph (shocking though it was) was intrinsic to her journey and so argued in favour of us being bold. For me, it captured perfectly how lack of awareness about hidden conditions can have devastating consequences for people with them. After *Tidings* hit the doorsteps, I received plenty of positive feedback from readers, vindicating the decision to go ahead. One particular e–mail still stands out. It was from a man who had suffered IBD for nearly three decades and, like Jessica, had had stoma surgery. He asked me to thank Jessica for being so courageous and sharing her story. He explained that he had experienced all the feelings that Jessica had spoken about: the loneliness, the isolation, the fear; and had faced them on his own, thinking he was in some way different to everyone else. As he said, such 'soft' things as emotions just weren't talked about when he had his surgery. For him, Jessica's article and photograph came too late, but he was grateful nonetheless. He was convinced it would help people in similar situations feel less alone with what they were going through.

Tidings spring 2019 front cover

I met Jessica at **Colostomy UK's** Open Day later that year and we have gone on to exchange the odd e–mail. On the health front, Jessica has needed no further surgical interventions since her J–pouch was fitted in July 2018 (her fourth bout of surgery in 12 months). This is of course good news, but she still suffers the effects of IBD. She continues to be plagued by frequent bowel obstructions and, because her rectal cuff is diseased, has occasional flare–ups. In July 2019 she was also diagnosed with chronic fatigue syndrome, which impacts her energy levels. On some days doing simple everyday tasks can be a struggle; it has even left her bed bound on a number of occasions. This makes what Jessica has achieved in the last 12 months or so all the more remarkable.

Early last year, Jessica set up a support group for people with bowel conditions in her local area, called Tamworth Super Poopers. As Jessica explained, she did this because she didn't want people to feel alone with what they were going through. The few meetings that took place before lockdown went well. 15 people attended, having seen Jessica's advertisements for the group on Facebook. The age range of attendees was very diverse. The youngest was in their 20s, the oldest in their 60s. People shared their stories and, in Jessica's words, "talked a lot about stomas and poo". The plan is to re–start face–to–face meetings as soon as Covid–19 regulations allow.

Photo: Ant Bradshaw
Style & Story International
Pageant Photography

Photo: Stuart Randle Photography – stuartrandle@outlook.com

Photo: This a selfie!

During lockdown Jessica has tried her best to continue supporting people with hidden conditions, by setting up a private Facebook group called IMVisible – Invisible Illness and Disability Support. Similar to the **Colostomy UK** private Facebook group, the aim of this is to provide people suffering with hidden conditions a safe place to 'meet', support one another and share experiences and tips. Jessica has also stepped beyond some of the more conventional forms of support. Drawing inspiration from the cover picture I mentioned earlier, she gathered a group of ladies together for a photoshoot creating a similar picture. Each participant used their own words to describe the negativity they encounter and fight, living with an invisible condition (from others and from within themselves). Naturally, many found the whole experience empowering. To see the photo and get a clearer idea of why this might have been the case, then visit the website that Jessica has setup, the name of which speaks for itself: **www.makingtheinvisiblevisible.org.uk**

The aforementioned photoshoot, while obviously being of great value to the people who took part, also contributed to Jessica's wider crusade to raise awareness of invisible conditions and the challenges people with them face on a daily basis. This is something she has been able to talk about recently in radio interviews with BBC West Midlands, BBC Radio 1, Wolverhampton FM and Radio Tamworth. She has also pursued in other ways too, including competing in beauty pageants, as a way of showing that beauty comes in all forms. When you look at the photos included with this article, you won't be surprised to learn that she has had some success. She finished in the top three for the Crown and Glory Pageant in August. She also competed in the Royal International Miss UK Pageant coming third in her category and second in the role model category. For me, the latter speaks volumes. In a society that places tremendous pressure on young women to look a certain way, Jessica is a role model. She is a role model for young women with hidden conditions. Through the pageants, she is outwardly saying you can be beautiful, even if you have a stoma bag. And, given her personal battles with ill health and the indignities of IBD, she is at the same time challenging modern ideals of beauty and showing that it is more than skin deep. Alongside the pageants, Jessica has also developed a range of what can only be described as 'awareness–creating' merchandise (Tee shirts, bags, calendar, car stickers etc) which she sells through her website. All proceeds from sales go direct to charity **(Colostomy UK included!).**

Drawing on a seemingly inexhaustible pool of energy, Jessica has been busy with other fundraising activities. Her plans to run a charity event in March last year had to be postponed for obvious reasons. But rather than shelve the idea altogether, she ran an online raffle instead, using some of the prizes that had been originally donated for the live event. This raised over £300, with **Colostomy UK** along with a number of other charities benefiting as a result. Buoyed by this success, Jessica then went on to run a number of other online charity fundraising events in 2020. These included a virtual pageant, where contestants sent in videos of themselves from home that went before a judging panel, with the winners then announced on Facebook. She plans to do a similar event this year, but this time round it will be a photo competition.

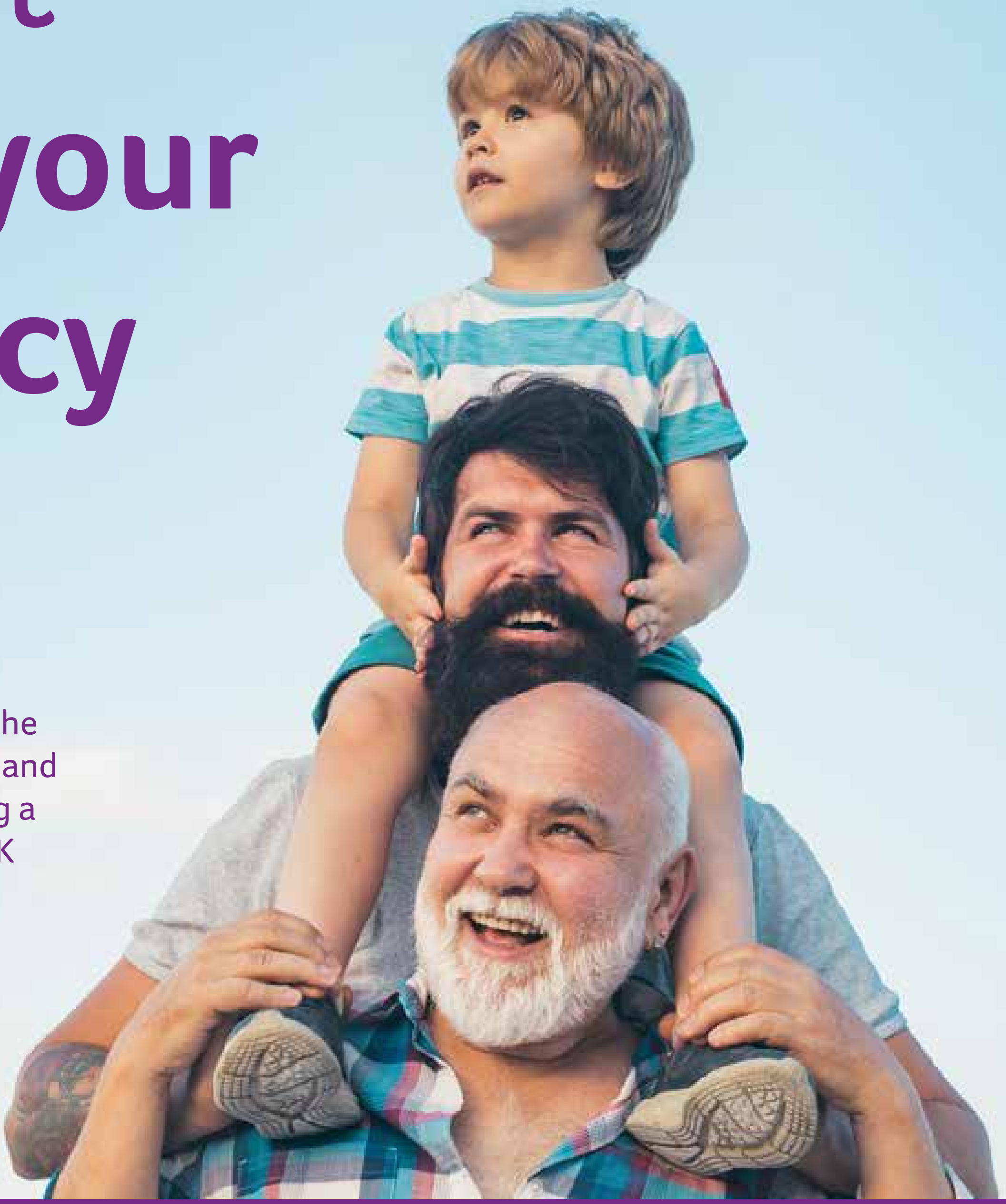
When I last spoke with Jessica, she was keen to tell me about some of her other plans for this year. These include delivering to schools and workplaces a talk she has put together about hidden conditions, which uses her own experiences to highlight the consequences of ignorance on sufferer's lives. She is also toying with the idea of a poster campaign, again focused in the Tamworth area. She intends to create a 2022 calendar, following the success of the one she did for 2021. And, of course, there will be the pageants. Rather than let her illness define her, Jessica has fought back and continues to do so. Her hope is to give others the courage to do the same.

Written by **Richard Biddle**

Photo: Ant Bradshaw Style & Story International Pageant Photography

Colostomy UK

What will **your legacy** be?



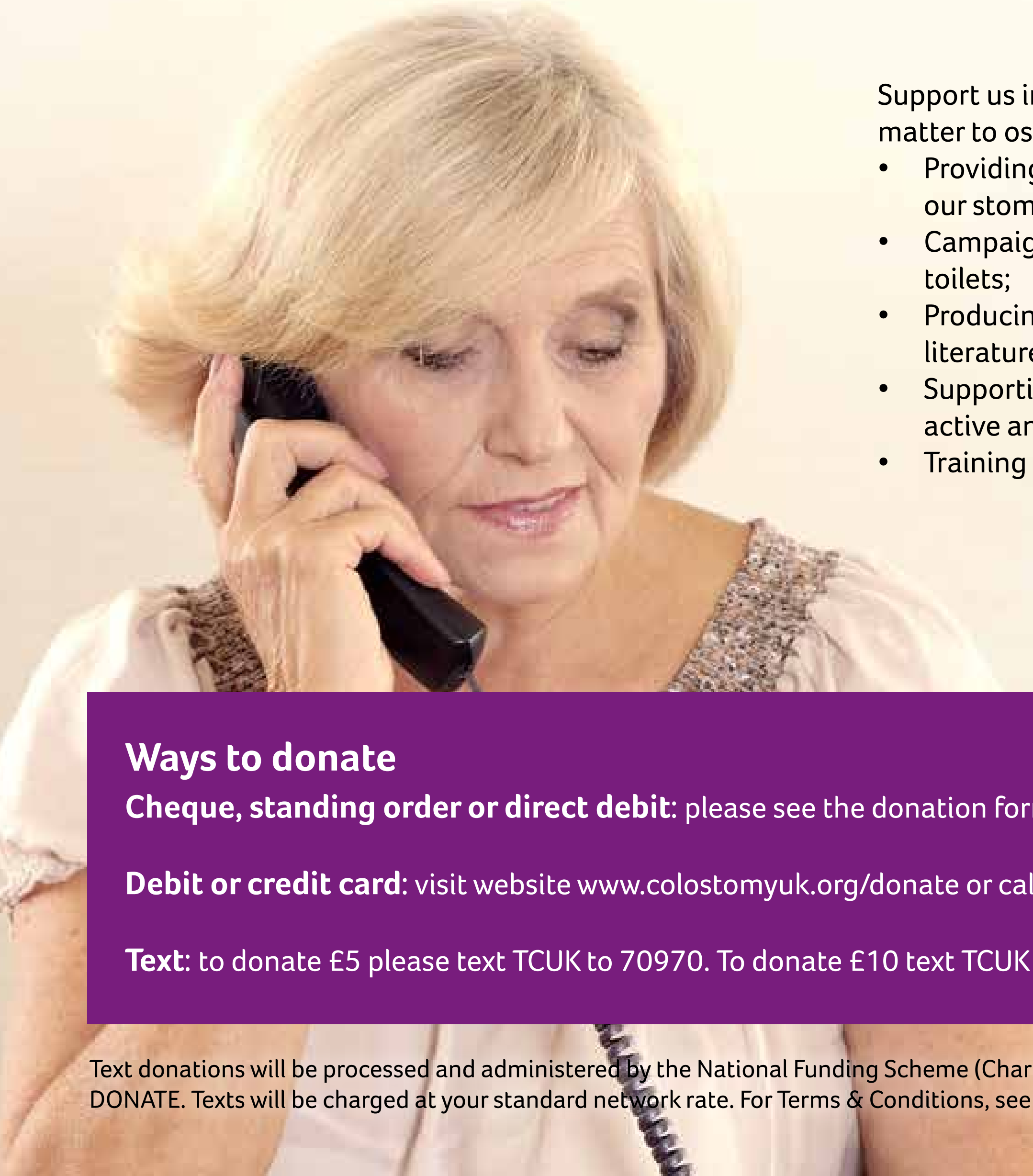
Help us to support the ostomates of today and tomorrow by leaving a gift to Colostomy UK in your Will.

Colostomy UK have been supporting ostomates like you, their family members, and carers for over fifty years.

With your help we can continue to do so for many years to come. A gift in your Will can help to ensure that services like our 24–hour helpline and Tidings magazine continue, while allowing us to develop projects that support ostomates' mental and physical health, train more carers to support those that need it, and continue to campaign for a more 'stoma aware' UK. If you'd like more information about leaving a legacy to Colostomy UK please call us on: **0118 939 1537** or email: **info@ColostomyUK.org**

Colostomy UK

The more you **do**nate, the more we can **do**



Support us in doing the things that matter to ostomates, such as:

- Providing 24 hour support through our stoma helpline;
- Campaigning for stoma–friendly toilets;
- Producing informative support literature and Tidings magazine;
- Supporting more ostomates to be active and healthier;
- Training carers to support ostomates.

Ways to donate

Cheque, standing order or direct debit: please see the donation forms on pages 41 or 42

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

Text: to donate £5 please text TCUK to 70970. To donate £10 text TCUK to 70191

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

Blocked stoma/bowel obstruction: a simple guide

Ambra Bertinara
Senior Stoma Care Nurse Specialist
NUH NHS Trust Nottingham

A blockage, also known as a bowel obstruction, leads to the output from your stoma slowing down or even stopping completely. The latter can happen suddenly. Blockages can occur either in the small or large bowel. A blockage can be described as partial or complete.

In a partial bowel obstruction, a small amount of liquid output manages to bypass the obstruction in the bowel, resulting in a liquid/mucous type of bowel motion from your stoma. In a partial bowel obstruction, you may still experience windy output from your stoma. In a complete bowel obstruction, the bowel is unable to release any output at all from the stoma.

Causes of blocked stoma/ bowel obstruction

It is not uncommon for people with a stoma to at some point experience a bowel obstruction. There are many different reasons why the small bowel may become obstructed. If you experience bowel obstruction, and you have been previously diagnosed with any of the following, you should seek medical attention by contacting your GP, Stoma Nurse Specialist or NHS 111:

- diverticulitis;
- inflammatory bowel disease, which may cause strictures or narrowing in the bowel which can cause obstructions;
- volvulus, otherwise, knows as twisted bowel;
- abdominal or parastomal hernia, which may cause strangulation of the bowel;
- adhesions or strictures in the bowel following colorectal surgery;
- recent abdominal or pelvic surgery; or
- bowel cancer.

But poorly digested food is the main reason for people with stomas developing a partial or complete bowel obstruction.

How do I know if I have a blocked stoma/bowel obstruction?

As mentioned above, the most obvious sign of bowel obstruction is that the stoma output slows down or may even stop altogether.

For people with a **colostomy,** a blockage could happen over several days and may start with signs of constipation.

For people with an **ileostomy,** a blockage can happen quickly in less than 24 hours. An ileostomy is generally quite active, with people usually draining their stoma appliance between five to seven times in a 24–hour period. With a bowel obstruction you may notice that you pass a reduced amount of output and need to drain your stoma appliance less frequently.

Other symptoms that you may experience are:

- abdominal cramping pain (may be near the stoma or the entire abdomen);
- swelling of the abdomen and/or stoma;
- decrease in urine output; urine may be dark in colour (this may happen from dehydration due to not wanting to drink fluids because you don't feel well); or
- nausea and/or vomiting.

Another symptom in addition to your output slowing down is stomach–ache. You may start to feel waves of cramping and abdominal pain, which may worsen if the symptoms you experience are unresolved.

What to do when you suspect a blocked stoma/bowel obstruction?

If you have an ILEOSTOMY and suspect you have developed a bowel obstruction, it is important to contact your Stoma Care Nurse Specialist or your GP urgently for advice. Some less severe blockages can be treated at home with the following tips:

- if your stoma starts to swell, replace your pouch by cutting the baseplate a little larger than normal to accommodate the swelling;
- if you have no output or only small output from the stoma, and you are not feeling nauseous or vomiting, stop eating solid food and only consume a liquid diet such as soup or warm broth, ice cream, plain yogurt;
- if possible, take a short walk; as long as it is not too painful. By keeping yourself mobile, you increase the blood supply in your bowel and therefore help your peristalsis movement (movement of the bowel's muscles) which should help to resolve the obstruction;

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CONTINUED FROM PAGE 57, COLUMN 2

- gently massage around your stoma or the whole abdominal area. As most blockages occur just below the stoma, this may help to dislodge the blockage; or
- a heating pad or a hot bath, may help your abdominal muscles to relax and remove the obstruction.

If you have a COLOSTOMY and suspect you have developed a bowel obstruction, you should contact your Stoma Care Nurse Specialist or GP for advice, who may prescribe laxatives to help you with the bowel obstruction. In addition to this, bowel obstructions can usually be treated at home with the following tips:

- drink plenty of fluids such as plain water, fresh fruit juices, tea or carbonated drinks;
- if you are not feeling nauseous or vomiting, introduce high fibre foods in your diet, such as fresh fruits and vegetables (always remove the skin to reduce the risk of further stoma blockages);
- if you are nauseous or vomiting, stop eating solid food and only consume a liquid diet such as soup or warm broth, ice cream and plain yogurt;
- if possible, take a short walk; as long as it is not too painful. By keeping yourself mobile, you increase the blood supply in your bowel and therefore help your peristalsis movement (movement of the bowel's muscles) which should help to resolve the obstruction;
- gently massage around your stoma or the whole abdominal area. As most blockages occur just below the stoma and this may help to dislodge the blockage; or
- a heating pad or a hot bath, may help your abdominal muscles to relax and remove the obstruction.

In both situations (ileostomy and colostomy) you should seek **urgent medical attention** by contacting your GP, Stoma Care Nurse Specialist or NHS 111, if you will show no improvement by following the tips given or if:

- the abdominal cramps will become more severe;
- there is no output from your stoma in the last 12 hours;
- You are showing signs of dehydration; or
- You are vomiting.

How can you avoid a bowel obstruction/blocked stoma?

If the bowel obstruction has been caused by poorly digested food, the following tips may help you to reduce the risk of developing a new obstruction in the future:

- chew the food really well, until you manage to break it down in small pieces. By doing this, you reduce the chances of pieces of food getting stuck in your bowel and ultimately causing an obstruction;
- take your time. Eat slowly so you give time for your body to chew, digest and assimilate your meals properly. 🟩

Got a particular topic you would like our Dear nurse to cover?

If so, then please email me at: **editor@ColostomyUK.org**

Colostomy Irrigation and You DVD

Order Form Colostomy Irrigation and You (Patients)

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

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

To obtain your single copy of *Colostomy Irrigation and You* at the special price of £1.99 (incl postage and packing) simply fill in your details below and return it with your cheque made payable to **Colostomy UK,** to:
Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA
or you can purchase online at: **www.ColostomyUK.bigcartel.com**

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Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA Charity No. 1113471 VAT No. 917079312

Halfx3 10v00r00 DVD Patients order form | Date of Publication: December 2020 | Copyright ©2018–2020 Colostomy UK | Registered charity no. 1113471

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

Colostomy UK

Looking for an easy way to fundraise?

Why not set up a **Facebook** birthday fundraiser?

Simply go into the fundraisers section on our **Facebook** page and follow the quick and easy steps.

https://www.facebook.com/fund/colostomyuk/

The funds you raise help us to support and empower people living with a stoma.

National support organisations

IA The Ileostomy and Internal Pouch Support Group
www.iasupport.org
Telephone: 0800 0184 724
e–mail: info@iasupport.org

UA Urostomy Association
www.urostomyassociation.org.uk
Telephone: 01386 430 140
e–mail: secretary@urostomyassociation.org.uk

Mitrofanoff Support
www.mitrofanoffsupport.org.uk
Telephone: 07903 382 013
e–mail: info@mitrofanoffsupport.org.uk

Purple Wings
www.purplewingscharity.com
e–mail: lauren@purplewingscharity.com

IOA International Ostomy Association
www.ostomyinternational.org

Junior Ostomy Support Helpline (JOSH)
via the Colostomy UK 24–hour free helpline: 0800 328 4257
e–mail: info@ColostomyUK.org

Bowel Cancer UK
www.bowelcanceruk.org.uk
Telephone: 020 7940 1760
e–mail: admin@bowelcanceruk.org.uk
Email Bowel Cancer UK nurses:
nurses@bowelcanceruk.org.uk

Macmillan Cancer Support
www.macmillan.org.uk
Telephone: 0808 808 0000
Monday–Friday, 9am–8pm

Crohn's and Colitis UK
www.crohnsandcolitis.org.uk
Telephone: 0300 222 5700
e–mail: info@crohnsandcolitis.org.uk

The IBS Network
www.theibsnetwork.org
Telephone: 0114 272 3253
e–mail: info@theibsnetwork.org

Stoma care open days

Attending a stoma care Open Day is an opportunity to find out about all the ostomy products and services available. It is also a chance to meet other people who have a stoma and visit the charity stands to talk to people who can give you advice and support.

Colostomy UK volunteers, all of whom either have or have had a stoma, attend stoma care Open Days all over the country whenever possible.

Due to Covid–19 open days are not currently being held. For an up–to–date list, including events in your area, check our website at: **www.ColostomyUK.org**

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

Stoma support groups
in your county

Channel Islands

Guernsey

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

Jersey

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

England

Berkshire

E.B.O.C (East Berkshire Ostomy Club)
Jackie Dudley T: 01344 426 652

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 or
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: http://www.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: www.cornwall-bowel-cancer-support-group.co.uk

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

Cumbria

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

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

Derbyshire

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: 0792 3975 051 or 01884 799 369

Plymouth & District Bowel Cancer Support Group
Wendy Wilson - Facebook: Plymouth Bowel Cancer

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

Replummed stoma support group
W: www.replummed.me

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

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

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

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

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

Herefordshire

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

Hertfordshire

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

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

Isle of Man

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

Isle of Wight

Optimistics
CNS's 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 or
T: 07948 974 350 or
E: dogs-uk@hotmail.com

Dover Stoma Friends Group Support
Carolyn Fullager T: 01304 821132.

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

M.O.G.S (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: www.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
Contact 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: 0208 235 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

Norfolk Ostomates Support Group (on Facebook too)
Barbara Harris T: 01603 417 046 /
07789 581 312

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: http://www.normandystomagroup.wordpress.com

Stoma Support Group
Robin Young T: 01428 723 255

Sussex

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

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

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

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

Warwickshire

Warwickshire Stoma Support Group
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: www.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: www.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: Secondchanceostomyyorkshire@gmail.com, T: 07544882353

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: www.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) Dublin
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

TEAM COLOSTOMY UK TRAINING VEST

100% sublimated polyester featuring printed **Team Colostomy UK** logo and **colostomyuk.org** on front and **#ActiveOstomates** on back.

Tight fitting order one size up.

£28.49 incl P&P

S	M	L	XL
☐	☐	☐	☐

TEAM COLOSTOMY UK BEANIE HAT

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Features: embroidered **Team Colostomy UK** logo on front. One size fits all.

£11.99 incl P&P

Colostomy UK

Kit and Merchandise

All proceeds from merchandise sales help us to get more ostomates physically and mentally active through our Active Ostomates project.

Find out more about Active Ostomates on page 24

SIZE GUIDELINES

All clothing items are a standard fit unless stated.

Small 34/36"
Medium 38/40"
Large 42/44"
X Large 46/48"
XX Large 50/52"

TEAM COLOSTOMY UK HOODED SWEATSHIRT

Team Colostomy UK 2019 Hooded sweatshirt.
Acrylic/ Cotton/Polyester mix.

Features printed **Team Colostomy UK** logo on front and **#ActiveOstomates** on back.

£35.49 incl P&P

	S	M	L	XL	XXL
Purple	☐	☐	☐	☐	☐
Charcoal	☐	☐	☐	☐	☐
Pink	☐	☐	☐	☐	☐

TEAM COLOSTOMY UK TRAINING SHIRT

100% Sublimated polyester featuring printed **Team Colostomy UK** logo and **colostomyuk.org** on front and **#ActiveOstomates** on back.

£33.49 incl P&P

S	M	L	XL	XXL
☐	☐	☐	☐	☐

#UPTHEPURPS T-SHIRT

Show your support for Team Colostomy UK Rugby League with our brand new **#UpThePurps** t-shirt.

100% cotton with Team Colostomy UK Rugby League on the back.

£18.50 incl P&P

S	M	L	XL	XXL
☐	☐	☐	☐	☐

SLEEVE LOGO T-SHIRT

Stand out from the crowd and show your support for **Colostomy UK** in our brand new Iris t-shirt.

Available in Sorbet
100% Soft spun cotton.

£16.49 incl P&P

S	M	L	XL	XXL
☐	☐	☐	☐	☐

COLOSTOMY UK T-SHIRT

Available in both purple and pink.

100% Heavy duty cotton.

Purple T-shirt

S	M	L	XL	XXL
☐	☐	☐	☐	☐

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