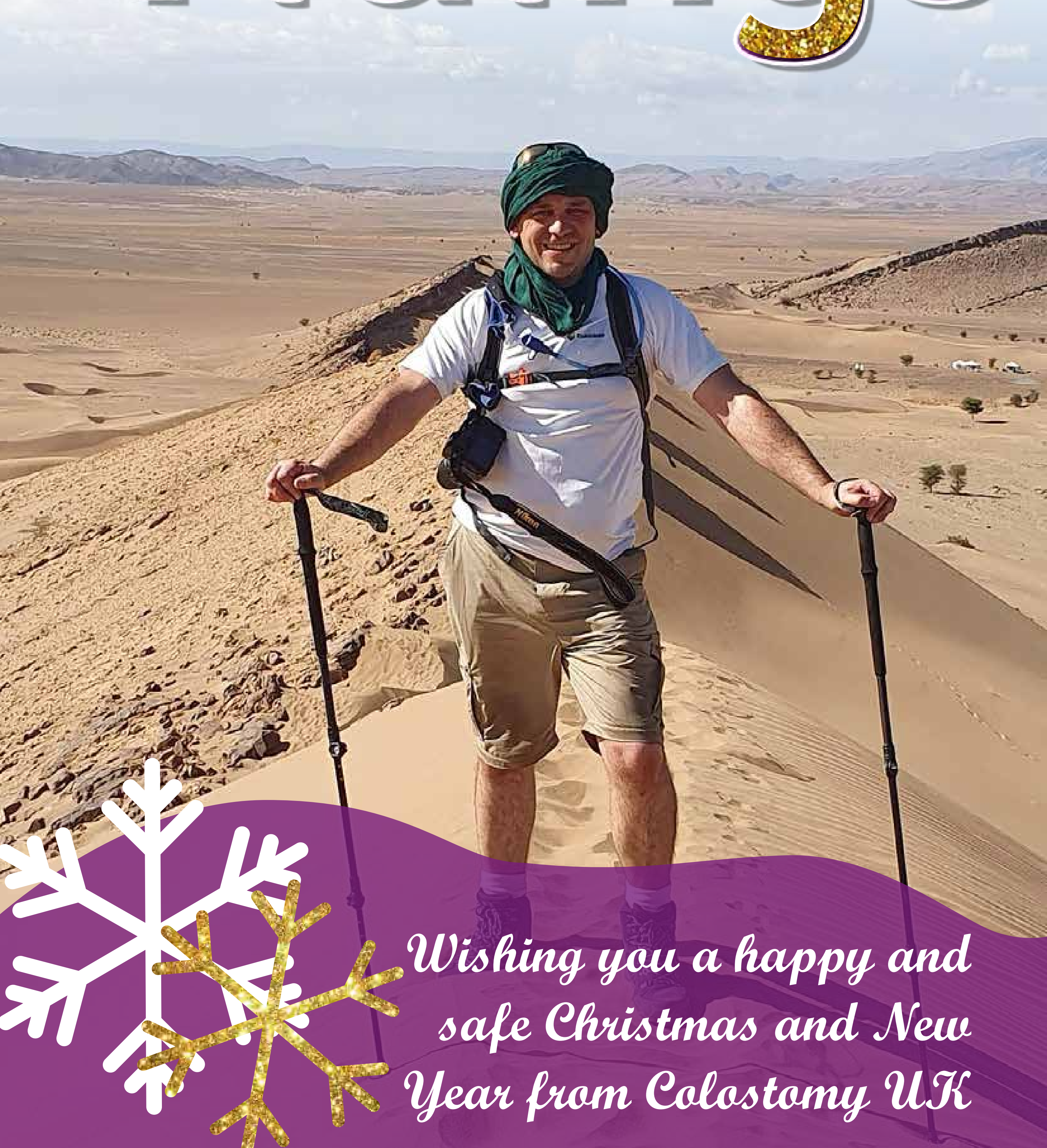
Winter 2020 | Issue 60

Supporting and empowering ostomates

Colostomy UK's Award Winning

Tidings



Wishing you a happy and safe Christmas and New Year from Colostomy UK

FEEL LIKE YOU AGAIN!

We believe in confidence and comfort for all Ostomates. We want you to be active, to be social, to be self-assured, to be the best version of you.

We are challenging stigma, fighting for Ostomate respect, and we will not allow you to be defined by your stoma. We are developing quality products to offer the support, freedom and quality of life that someone living with a stoma deserves.

But we are demanding more... more comfort, more discretion, more simplicity, and more choice.

That's why we are committed to innovating our stoma care bags, and developing products that are both stylish and comfortable.

Be part of the movement.

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Dear readers

Colostomy UK

This will be our third edition of *Tidings* put together in the dismal light cast by the coronavirus. As the number of cases of Covid–19 took a sharp upward turn in September, we were forced to close our offices again and return to remote working. This means that requests for our literature, along with things like RADAR keys and ID cards will take a little longer to come through – so thank you once again for your patience and understanding. Just as we did in the spring, we will be doing our best to keep supporting you. But sadly, as Libby Herbert our General Manager outlines on page 6, the events of this year are starting to put financial pressure on the charity

I'm sorry for such a gloomy start and as I sit here now writing this to you, I have to be honest and say that it's a bit of a struggle to muster much in the way of Christmas cheer! If, like me, this pandemic thing is getting you a bit down in the dumps, then I'm hoping you will be buoyed up a little by what we have in store for you. We have a great set of real lives stories. In a truly inspiring piece, Dave Thraves, who sustained a terrible injury as a young man, explains how his recent colostomy has transformed his life. Joanna Prance, another new colostomate, shines a light on a subject long overdue attention: anal incontinence following traumatic childbirth. Jo Easterbrook and Molly Belling use their experiences to give new ostomates some valuable tips and words of encouragement. We also hear from Lynn and her partner Phil who, within 14 months of meeting, both underwent stoma surgery! We then round things off with Chris Morrison, who I interviewed about his post–operative journey back to work as a firefighter and how a once in a lifetime trip helped him come to terms with what he and his family had been through.

Thankfully, the pandemic hasn't prevented contributions from healthcare professionals. I am grateful to Mark Johnson, who is a clinical nurse specialist with Fittleworth Medical Ltd, for writing our Dear nurse feature, which looks at stomas and bleeding. Jennie Burch, who some readers will recognise and who is Head of Gastrointestinal Education at St Mark's Hospital, talks about dementia and stomas. With an ageing population, this is a subject that I think we will all benefit from knowing something about. Ian Daniels our President and also a consultant colorectal and general surgeon, outlines some of the reasons why a colostomy is sometimes changed to an ileostomy. This is something that we are asked about on the stoma helpline from time to time. The surgical perspective Ian gives is then looked at from the patient's point of view with two 'mini' real lives stories from Karen Quinn and Sue Hatton.

Finally, there are all the usual updates from **Colostomy UK,** including some exciting news about our new **#StomaAware** campaign. We launched this in October to coincide with World Ostomy Day. Indeed, you may have picked it up in the news. The coverage was the best we have had in the charity's history!
On that positive note, I'm going to sign off by wishing everyone a merry Christmas and a happy (please!) New Year.

Merry Christmas and a happy new year

Richard Biddle
Editor,
Writer & Researcher

Stoma
Skin
Soul

It’s good to stick,
but not get stuck!

Coming soon the new SMILEY **cut** release liner.

It will make you smile!

For more information please call **0800 581117**

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Contents

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

Colostomy UK
Enterprise House, 95 London Street
Reading, Berkshire, RG1 4QA

info@ColostomyUK.org

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

Arvind.Anand@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!

Colostomy UK news

Real lives

Wellbeing

Fundraising

Support

Donating to Colostomy UK

An annual donation of £20 (or whatever you can afford) allows us to produce *Tidings* and to continue our vital work, supporting, and empowering ostomates – see page 8 for donation form.

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

An important message from Libby Herbert, Colostomy UK's General Manager

Colostomy UK

Date: December 2020

Dear Tidings Readers

Back in February, as the first cases of coronavirus appeared in the UK, few, if any of us, could have predicted the huge impact it would have on all our lives.

At **Colostomy UK** we are proud that despite the difficulties 2020 has brought, we have managed to keep on supporting the ostomate community. This has happened because of the supreme effort made by our office team and volunteers, who have embraced new ways of working, as well as developing solutions to keep our services and projects running.

Our popular Active Ostomates® sessions (normally delivered in partnership with stoma support groups at group meetings) are now available and freely accessible to all online. As well as chair yoga and art we have also added Mindfulness and Meditation classes. Our 24–hour Stoma helpline has stayed open at all times and we have added an instant messaging service so that visitors to our website can contact us online as well as picking up the phone. We are also developing a telephone befriending service to offer better support to those feeling more vulnerable and isolated during these difficult times. We have also continued to produce Tidings. Recent feedback suggests that people particularly welcomed receiving this while other parts of their 'normal' life have been restricted. We have also managed to keep fulfilling requests for our literature, supplying ostomates and stoma care nurses alike with all the titles in our range. We haven't stopped our advocacy work either. We have continued to speak for ostomates at the Patient Industry Professionals Forums and the Scottish Stoma Forum. Our work with airports has also re–started.

But, while it's been a great year, I'd be lying if I didn't also say it's been a very tough year too. Lockdown took its toll on the team as we adapted to working remotely, while at the same time doing our best to respond to the ever–changing situation. As we said in the last edition of Tidings it's been challenging for our volunteers too. Of course, we aren't unique. Nor are we different from other charities in that it has had an impact on our sustainability. Our donations have fallen and the advertising revenue from Tidings is down – making this magazine, which people love so much, only just viable. And it's important to stress that Colostomy UK doesn't get government aid or statutory funding. Hence, I'm going to finish this message with a plea, which is that you donate if you can, so we can keep the good work going in 2021 and beyond.

If you would like to set up a regular donation you can do so by completing and returning the direct debit or standing order sections on the form on the page opposite. You can also use this form to send us a one–off donation.

Our website **www.colostomyuk.org/donate** accepts credit and debit card donations. You can also set up a direct debit mandate online.

Please support us so we can continue to support you!

With all my best wishes for the festive season.

Libby

Libby Herbert
General Manager

Colostomy Association Ltd trading as **Colostomy UK**
Registered address: **Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA**
T: **0118 939 1537** W: **www.ColostomyUK.org** E: **info@ColostomyUK.org**
Stoma helpline: **0800 328 4257**
Registered Charity No: **1113471** Company No: **05623273** VAT No: **917079312**

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

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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.

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- 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.

Make a donation

Colostomy UK

Without **donations** from people like you, **Colostomy UK** could not continue its vital work **supporting** and **empowering** ostomates. Thank you for supporting us.

My Details: Title: Forename: Surname:

Home address:

Postcode:

Telephone (home): Mobile:

Email:

Date of Birth: Month and year of operation:

Reason for your stoma: Stoma type: ☐ Colostomy ☐ Ileostomy ☐ Urostomy

Tick as appropriate: I would like to be kept informed by: ☐ Post ☐ Email ☐ Telephone. Please tick if you would like a receipt ☐

I would like to receive information about: ☐ Tidings magazine ☐ Bag and product manufacturers ☐ Colostomy UK, the work it does, including training, conferences, volunteer opportunities and fundraising.

We will never sell or swap your information with other organisations. You can change how we communicate with you at any time.

Call us on: **0118 939 1537** or email: **info@ColostomyUK.org**

I would like to make a donation of:

☐ £20 ☐ £30 or whatever you are able to give £

☐ 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.

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Name: (IN CAPITALS)

Signature: Date: / / 2020 T60

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Registered Charity No: 1113471

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

Spotlight on... ..SALLY

Volunteering during a pandemic

It feels like a large chunk of this year has been spent adjusting to new ways of living, working, and volunteering. At Colostomy UK we are lucky to have such a dedicated and committed team of volunteers. Despite all that the pandemic has thrown at us, they have remained steadfast and ever ready to support ostomates in need. Without them it would have been impossible for us to provide all our support services without interruption. I'd like to take this opportunity to say a **BIG** Thank You! to our volunteers for their hard work this year and wish them all a restful and well–earned Christmas break!

As you may recall from the autumn edition of *Tidings,* I mentioned that we had had to postpose the face–to–face volunteer training we planned for March. This was a real blow for us, causing as it has, delays in new volunteers starting. Over the summer we worked on 'translating' our training into modules that we could deliver online using, for example, Zoom. I am pleased to report that we have now started to deliver this. Safeguarding training for new and existing volunteers started in August and is ongoing. Our 'Introduction to **Colostomy UK'** sessions for new volunteers began in October and, by the time you read this, our 'Stoma Helpline' training will have commenced. This means that by early 2021 (if not before) there will be some new voices on the end of the phone!

So, who are these volunteers I keep speaking about? As Volunteers' Manager I'm privileged because I get to know our volunteers and work with them in many different ways. Believe me, they are an enthusiastic bunch with a wealth of experience and skills. They are also very personable, caring and 'normal' people. Over the past few months, I've been racking my brains, trying to think of a way to show this side of them to you. My solution is the **Colostomy UK** equivalent of 'Desert Island Discs'. Let me introduce you to Sally, who had her stoma surgery in 2014 and has been a volunteer with us since 2016. If you call the helpline you may well speak to her!

Emma: Tell me what made you volunteer for **Colostomy UK?**

Sally: *I joined to help others who have been through the same thing as I have. I remember early on in my journey that the more I talked about my condition and my treatment the less fearful I was. As my experience of my condition grew so I became more confident in helping others.*

Emma: Knowing what you do now, what is the one piece of advice you would give to a new ostomate?

Sally: *Don't panic as things are going to be strange but it is all manageable. At your first opportunity, and if you are able, irrigate.*

Emma: What do you enjoy most about being a Colostomy UK volunteer?

Sally: Steering people in the right direction to put them in the best position to cope and enjoy their life under their new conditions.

Emma: Tell me about your hobbies and pastimes

Sally: I Zumba once a week, go to Fitsteps twice a week and Verflow (a form of yoga) once a week. All these are physical, low impact exercises with stretching – all of this helps with toning and fitness. I knit, cross stitch, and play Pokémon Go and Animal Crossing New Horizons at every opportunity!

Emma: What was the last thing you read?

Sally: My latest novel was The Noble Path by Peter May, a thriller based in 1978 and set in Cambodia and Thailand during the Khmer Rouge regime. Initially I discovered Peter May through his Lewis trilogy series of books and have become an avid follower ever since.

Emma: If you won the lottery, what would be the first thing you bought and why?

Sally: I would buy houses for all of our children so I could secure their futures.

Emma: What is your most prized possession and why?

Sally: My Kindle is my most prized possession because it keeps me in contact with my family and friends, holds all of my photographs, provides me with a wealth of music and holds all of my reading material.

Emma: What's the most stupid thing you've ever done?

Sally: Undoubtedly, the most stupid thing is trying to ride a bike. I failed miserably, falling into hedgerows on my way.

Emma: What's your favourite food?

Sally: I like Italian food because of the pasta and sauces none of which upset my digestive system.

Emma: If you were marooned on a desert island, what three things would you want with you and why?

Sally: I would take and in no particular order, my Kindle, my knitting needles and my irrigation kit.

If, like Sally, you have a passion for helping people and want to make a difference to the lives of fellow ostomates, then why not check out our website for current volunteering opportunities? Or, if you prefer, drop me an e-mail: volunteer@ColostomyUk.org. Happy Christmas!

Colostomy UK: news

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

#StomaAware Day

The first Saturday in October is World Ostomy Awareness Day. It's always been an important date in the Colostomy UK calendar, particularly as we were on the founding committee that co-ordinated the first one back in 1992! Since then, it has become a celebration for ostomates all over the globe.

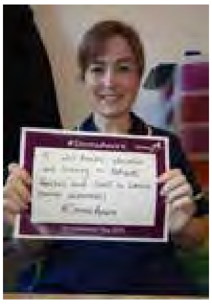
This year, we used the day to hold our first StomaAware Day and launch our new campaign of the same name. We believe that being 'Stoma Aware' is something we should focus on all year round. If we are to realise our vision of a stoma–friendly society, then we mustn't ever let up on spreading awareness of stomas to society! Our new campaign will build on all our previous work and take it to the next level.

We will be announcing full plans for our StomaAware campaign in 2021. But launching the campaign on World Ostomy Day was obviously a smart move as we ended up with a feature on the Sky News that reached over 500,000 people. We then had another slot on Sky News the day after featuring our ambassador Sarah Smith and Libby Herbert our General Manager.

We were also delighted to see how the stoma community and some of our fellow charities, including Target Ovarian Cancer and Fight Bladder Cancer, embraced **#StomaaAware** Day and our call to arms. They helped tell the world what we were doing and explained why they were **#StomaAware.** Some of the images that were shared on social media can be seen below.

Although I don't want to reveal too much at this stage, part of the new campaign will be working with organisations to help them BECOME Stoma Aware. So If you work for an organisation that you think would benefit from Stoma Awareness training please contact: **info@colostomyuk.org.** We can deliver this online, so there is no reason to delay!

For more on our new campaign visit our website: **https://www.colostomyuk.org/stomaaware**



Bristol University Life Drawing

Back in September we were contacted by medical students from the Bristol University Gastroenterology and General Surgery Society and the Arts in Medicine Society about collaborating with them on a project aimed at promoting awareness and sensitivity about stoma care and living with a stoma. As medical students they are taught about stoma surgery and stomas as a treatment option. However, in their teaching, there is little exploration of the after–effects of stoma surgery on patients' lives, (negative or positive). The societies want to bridge this gap by running a series of online (ZOOM) 'life drawing' classes, in which an ostomate will be the 'model' and the classes will be attended by medical students. The model's experiences of life with a stoma will then be explored through drawing and discussion.

At the time of writing we are just a few days away from the first session taking place. Fingers crossed it will go well. We will report back in the new year!

A chance to have your say!

Patient Feedback survey on services provided by Dispensing Appliance Contractors (DACs) and Pharmacies.

The British Healthcare Trades Association, who represent Dispensing Appliance Contractors (DAC's) in England, are looking to set up a patient panel to give feedback on the services provided to patients for their stoma appliances from DACs and Pharmacies. The panel will consist of approximately 300 patients who have had a stoma for at least 12 months and are willing to submit feedback via an on–line form every three months for at least 12 months ie four survey responses per year.

The survey will consist of two parts; the first part covers the requesting of your next appliances and the second part about the delivery of your appliances by your DAC. Each survey response will take no more than 10 minutes to complete and submit.

In order to take part in the survey we will be looking for participants from all areas of England and users of all DACs or pharmacies and will be limited to 300 participants. We will need your name and e–mail initially and will raise a member number that can then be used as a reference during the survey period.

- 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.

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

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

You can register to take part through the following web link **https://cfep.net/wKx3LR** and once we have the full panel in place, we will contact you with further background information on the survey objectives and process. We will be aiming to begin the first survey in mid–September 2020 but will update all panel members once this is agreed.

Colostomy UK Team news

Welcome Lucinda Mitchell

Lucinda Mitchell,
Marketing and Communications Manager

Lucy joined Colostomy UK in November 2020 as our Marketing and Communications Manager. Formerly the Senior Marketing Executive at Phyllis Court Club in Henley, she brings with her nearly 10 years' experience in marketing and she is going to need it! She will be in charge of building and delivering our marketing strategy and managing our website and presence on social media.

Born and raised in Berkshire, Lucy has always had a passion for her chosen career. While she was studying Business and Management with Marketing at the University of Bath Lucy volunteered with the Alzheimer's charity, RICE, and learnt about the important part that marketing and communications play in charitable organisations. On leaving university she worked for the charitable arm of a private school, Bradfield College. Today she has experience in both corporate and charitable settings, which she can draw on in her new role.

When she isn't at work, Lucy can be found indulging her lifelong passion, horses. She began riding at the age of six. Although her focus is now show jumping, when she was a student, Lucy played polo at a national level with SUPA. Lucy loves socialising and attending events, especially if there are cocktails! She is very passionate about the environment and climate change. In her role with Phyllis Court, she joined a sector wide campaign, to lobby supply chains to eliminate single use plastics, and had some successes.

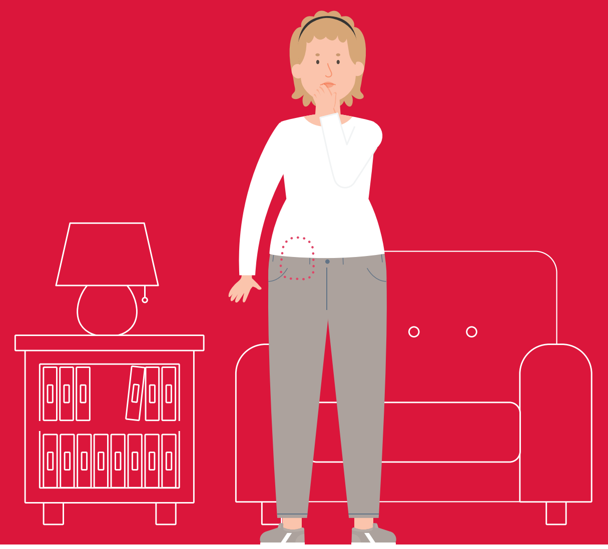
Commenting on her appointment, Lucy said: "I am delighted to join Colostomy UK at such a pivotal point in its history. I look forward to using my knowledge to extend the charity's reach, tell the wider world about stomas while, of course, supporting and empowering ostomates!"

Goodbye to Clare Matthews

Lucy's appointment sadly means a fond farewell to Clare Matthews, who stepped up to support us on a part–time basis back in February. This was Clare's second stint with us and she has been an invaluable contributor to our charity at a very challenging time through the pandemic.

Thank you Clare!

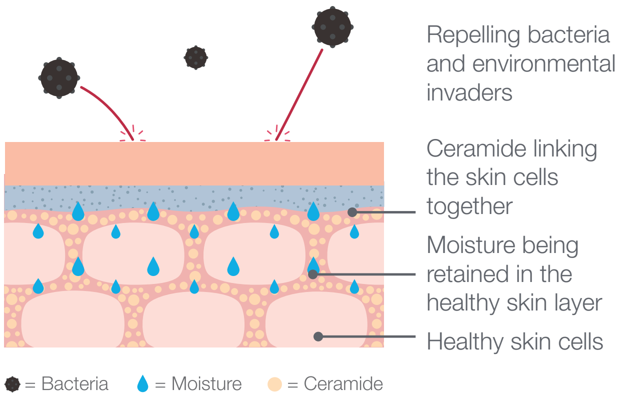
Healthy skin can mean a happier you



The condition of your peristomal skin can impact how well your stoma pouch adheres to your body, as well as your general comfort and wellbeing.

How does your skin stay healthy?

The skin has an important role for the body. One component that helps keep it functioning at its best is called ceramide. Ceramides[1] are waxy lipids that act like mortar between your skin cells. This helps to minimise water loss from your skin, which can lead to dryness and leave your skin vulnerable to further breakdown.



The CeraPlus™ Skin Barrier with Remois Technology*

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Order your sample here **TODAY**.

[1] Coderch L, Lopez O, de la Maza O, Para JL. 2003, Ceramides and skin function. Am J Clin Dermatol. 4(2):107-129. (v1.0) p. 2, 7.

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

*Remois is a technology of Alcare Co., Ltd

Remois

Hollister®

Ostomy Care
Healthy skin. Positive outcomes.™

My dignity has been restored

Dave Thraves

My name is David Thraves. Back in 1992, when I was 27 years old, a company director of a fire and flood restoration business, living in my own home, engaged and enjoying an active social life, my future, at a stroke, changed immeasurably.

On the 26 August of that fateful year, whilst holidaying in Majorca, I was involved in a serious diving accident which left me paralysed from the neck down. Following a brief ten–day stay at an intensive care unit (ICU) in the capital, Palma, an air ambulance was chartered (with the financial assistance of my holiday insurance) and I was flown back to the UK. Under the blue lights of a cautiously driven ambulance, I was taken to ICU at the now closed Salisbury General Infirmary and, after approximately two weeks there, was transferred to The Duke of Cornwall Spinal Treatment Centre at Odstock, Salisbury. I spent a further 12 months rehabilitating at the spinal unit, before moving onto a nursing home situated on the outskirts of Bath, the city where I had lived since the age of 17. For two years I was a resident at Shockwick House Nursing Home, a historic manor house built around 1750 by John Wood the elder. During the years spent at the nursing home my house was sold, another house was sought and, following a relatively lengthy period of time, converted for my needs. My journey through the many medical institutions involved in my recovery, staffed by some of the most selfless and professional people I'd ever known, now ended. Living independently at home with my own personal assistant (PA)/carers courtesy of the then recently launched Direct Payments scheme, I finally regained my independence and control of my life.

Because of the paralysis that accompanied my spinal injury, I was incapable of moving my body from the neck down. Consequently, I was unable to carry out any of my own bowel care. Whilst rehabilitating at the spinal unit in Salisbury, my bowel care routine was administered by a member of staff and triggered with the use of glycerine suppositories and a gloved lubricated finger. When it was deemed I had finished, the member of staff managing my bowel care checked my rectum was empty in order to prevent embarrassing accidents occurring later on. Having done so, they would move me into the shower. My bowel care took approximately an hour to complete and I was sat over the toilet in my shower chair for the duration of the procedure. By the time toileting and showering had finished, I had been sat in my shower chair for approximately one and a half hours. Initially, there were few problems, although the comfort level of the suppository bowel care I received was partly dependent upon the person carrying out the task. Constipation, diet, water intake, laxatives etc. also affected how comfortable my bowel routine was.

When I moved from the hospital to the nursing home, a limited number of staff were trained to carry out my bowel care. Despite the limited numbers and training given, this occasionally resulted in discomfort and bleeding. In hospital, I had developed a small pressure sore area in the gluteal fold – the crease line situated where the top of the upper thigh meets the buttock – and this pressure sore duly caused me a great deal of trouble over many years!! During the years that followed my accident other bowel issues emerged, including haemorrhoids and autonomic dysreflexia. The latter is a syndrome that affects people with a spinal injury at the T6 level or higher. Amongst other things, autonomic dysreflexia can be triggered by bowel issues, the symptoms being a sudden onset of excessively high blood pressure, perspiration, cold clammy skin, flushed face with red blotches on the skin and, if left untreated, a pounding headache and a potentially life–threatening prognosis. Thankfully, although I suffered many of the symptoms, I avoided the last! Whilst living in my own home, even with the most experienced and diligent of PA/carers, occasionally my bowels would open again while showering. I could grin and bear the discomfort, but something as undignified as your bowels opening in the shower eventually prompted me to seek an alternative form of bowel care.

CONTINUED ON PAGE 15, COLUMN 1


S.T.A.R.S.

CONTINUED FROM PAGE 13, COLUMN 3

Over the years, the pressure sore that I spoke of earlier, remained small due to the dedicated and professional supervision received from those involved in my care. However, during this period, I spent countless days, weeks, and months on bedrest, desperately trying to avoid a more serious pressure sore developing. Despite alterations to my electric wheelchair, different pressure relieving cushions, an air mattress for my bed, and the huge experience and knowledge of the spinal unit, the mark persisted albeit in a managed way. Nobody seemed able to answer why the skin broke down. With all the problems that had amassed as a result of my bowel care, combined with the challenging times I had spent on bedrest, a solution had to be found.

Following discussions at the spinal unit, a referral was made to Mr Graham Branagan, the colorectal consultant at Salisbury District Hospital. Having exhausted numerous methods of bowel care over the years, Mr Branagan told me that, in essence, my options were limited to either continuing with my current bowel care routine or having a colostomy. I had never given much thought to a colostomy as it was rarely, if ever, discussed during my hospitalisation back in the early nineties. I had tried all sorts of different potions and lotions to help with my haemorrhoids, to assist intestinal transit, and to counter the effects of autonomic dysreflexia. However, apart from managing the dysreflexia, remedies for the other issues were tried, but all to no avail. In reality, the choice left to me was to put up with the status quo or go for the colostomy. Well, my decision making was further aided by the fact that, following the pressure mapping of me sat in my shower chair, it was a revelation to discover that high readings were noted in the gluteal fold area of my body, the area that had given me so much trouble for so many years. Pressure mapping is simply a pad with sensors that you transfer onto in order to provide a snapshot, or live feed, of the pressures under the seated surface. So, in conclusion, after more than two decades managing the pressure mark and years of bowel care related problems, having weighed up the pros and cons of having a colostomy…it was a no–brainer really, and I gave the green light for the operation to go ahead.

On the 23 November 2015, the colostomy operation was carried out at Salisbury District Hospital by Mr Branagan and his highly professional team. Afterwards, it only took a short period of time to adjust to the new form of bowel care. The benefits were felt reasonably quickly. It took about seven days post–op for my blood pressure (BP) to settle. The spike in BP I experienced was almost certainly caused by the effects of autonomic dysreflexia and once the correct medication was put in place to calm it, the situation rapidly improved. Within a matter of weeks everything settled, and because I no longer had to sit over the toilet, I was able to cut the time spent in my shower chair by 70%. Within six weeks of the operation, the once invincible pressure sore had all but disappeared! The loathsome bedrest that had formally blighted my mobility has not been needed since and is now a distant memory. My dignity has been restored, because the unwelcome bowel movements that every so often played havoc during showering, are now at an end.

There have been other benefits from having a colostomy. The autonomic dysreflexia that troubled me during toileting for far too many years to mention has disappeared and, with it, all the associated symptoms. Another benefit for having opted for the colostomy, is that I no longer have to worry about how conscientious somebody new might be whilst carrying out my bowel care. Training somebody to change a colostomy bag is infinitely easier than training someone to use suppositories and digital stimulation. The humiliation of explaining to a new member of my care team, or for that matter an agency carer, the 'Russian Roulette' likelihood of a post–toilet accident, is now a thing of the past. Previously, when travelling abroad or staying away with friends and family, a good deal of consideration had to be given to the bathroom facilities. Amongst other things, the toilet had to accommodate my shower chair. We would we have to consider the time it was going to take to carry out my bowel care and also have to factor in a recovery time or, if that wasn't possible, revert back to the 'grin and bear it' approach. Such issues are now banished to the annals of time.

So, as you can imagine, for me the colostomy operation has been a revelation. Thing is, it didn't just affect me, it also affected my family, friends and PA/carers. Before the colostomy 'Bedroom Bistro', a coin of phrase adopted by those that came to visit me for dinner whilst I was on bedrest, is now something we reflect on with amusement. Whereas it was common for me to decline an invite due to bedrest, such restraints are no longer a consideration. Training a new PA/carer to change my colostomy bag, frees me from the awkwardness of explaining my suppository bowel care. Post–op travelling is a breeze compared to what it used to be and places that would have otherwise been inaccessible, are now a possibility. The morning pain and discomfort that once spoilt and blurred my daily living is greatly reduced. I still suffer with root pain, a form of pain associated with spinal injury, but at least I don't have to contend with them both.

Having lived with the colostomy for almost five years now, I can honestly say that the benefits vastly outweigh the negatives. Some people have asked me if the aesthetic side of having a colostomy bothers me. Well, anybody in an intimate and physical relationship would almost certainly have given this due consideration, but seeing as there are some very discreet colostomy bags available, and considering the health and well-being advantages that I can attribute to having had the colostomy, I'd say no.

Nowadays I rarely, if ever, think about the colostomy at all! As I explained earlier, it has given me back the ability to live my life free from the spectre of pain, discomfort, and bedrest. It has also liberated me from the mental humiliation associated with my previous bowel care routine. It has made me more confident and able to reliably put my name to things. I used to give talks in schools, colleges, universities, hospitals and wherever else would have me, but the worsening situation that once affected my bowel care combined with the constant worry of letting people down and the challenging effects of pain, left me with no alternative but to often cancel or decline. I thoroughly enjoyed carrying out these presentations, and now that the colostomy has freed me to do such things, hopefully soon I'll be able to return to offering the presentations I felt so passionate about. Like many things in life that are new, it takes a little time to adjust to change. Minor issues are soon ironed out or managed. Many things in life come with consequences or compromises, but in the case of the colostomy, these are very much mitigated by the benefits. I wish I had opted for the operation decades ago, as for me, it has been life changing! 🟩

Dave's Jack Russell, Ronnie, has just had a chest op. It was the vet's suggestion that he wear a tee–shirt!


Genii
Genii

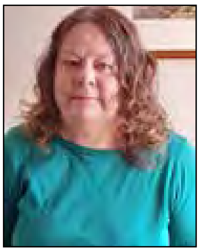
Colostomy to ileostomy…

Editor's note: from time to time we receive calls to the Colostomy UK stoma helpline from people who are about to have surgery to change a colostomy to an ileostomy. They have a whole range of questions including: How will it affect my output? Will I be able to eat the same things?

Ian Daniels, our President and also a consultant colorectal and general surgeon, had this to say about the reasons why such surgery is sometimes undertaken:

> *The need for a colostomy may follow a bowel cancer operation and some people have an increased risk of a second bowel cancer in the remaining bowel. This is often related to a group of conditions called hereditary non–polyposis coli (or Lynch syndrome). Should further polyps (the precursors to cancer) develop or a distinct genetic factor be identified that indicates a lifetime increased risk, there follows a conversation about the person's future care and risks/benefits of further surgery versus increased colonoscopic surveillance. Obviously if a second cancer, a large polyp or large number of polyps is found, we would recommend removal of the remaining large bowel (colon +/– rectum if it remains) as this is both a treatment, but a future risk–reduction strategy, the result being an ileostomy.*
>
> *Other reasons for conversion to an ileostomy from a colostomy include: poor colonic function, people with Crohn's disease of the colon and rectum (alone), extensive and recurrent diverticulitis, and as an emergency if there is evidence of bowel obstruction or perforation.*
>
> *In terms of function there are some differences and some dietary and lifestyle changes, and your stoma care nurse would be able to help with this. There are also excellent articles in previous Tidings, but overall it shouldn't impact any differently on living an independent life.*

We are also lucky to have two stories from people who have had the surgery. They explain why it was necessary and, through their experiences, start to answer some of those common questions we get on the helpline.



Karen's story

Karen Quinn

When I caught up with Karen in late June, she was around five weeks post–op and recovering well following a full reversal. For Karen, it marked the end of a stoma journey that began back in October 2013 when, without warning, she became unwell.

At first Karen thought she was constipated and so didn't seek medical advice, but when her abdominal pains started to get worse over the weekend and she began to run a temperature, she arranged to see her GP on the Monday morning. Karen's GP immediately referred her to the hospital as Karen was displaying all the classic signs of diverticulitis. At hospital, this diagnosis was confirmed within a couple of hours, during which Karen had a CT scan, x–ray and other tests. Karen spent a week in hospital where she was put on intravenous (IV) antibiotics and had a mixture of IV paracetamol and morphine for pain relief. What Karen didn't realise was that this 'episode' was just the first of many more to come. Between October 2013 and her first bout of stoma surgery in February 2018, Karen was hospitalised a further eight times. Her surgeon explained that some people with diverticulitis have flare–ups and then these stop, hence his preference was to adopt a conservative approach, with surgery being the last resort. Eventually though it became clear that there was no other option.

After her eighth flare–up Karen was booked in for stoma surgery, but this was cancelled on the day. She then had her ninth and final flare–up (after 12 weeks of constipation) and was admitted as an emergency case, as her bowel was in danger of bursting. By this point Karen had made a number of visits to the colorectal ward and so had some understanding of what a stoma was, although by her own admission, she had purposely not gone out of her way to find out too much. All she knew, was that she didn't want one. On the way to theatre she pleaded with the surgeon for a resection if this was possible, but when she woke up post–op, she says she knew she had a bag. She even remembers saying to the nurses in recovery: "I've woken up with a bag, haven't I?".

Karen's experiences in those early days in hospital and then at home will be familiar to many readers. At first, she couldn't even bear to look at her stoma. In the end, desperation to get home proved a great motivator and Karen successfully did her first bag change. Reflecting on this period, Karen is of the opinion that hospital was starting to become a comfort zone for her, as there was always someone there to help her. After a four–week hospital stay Karen began the slow process of adjusting to life with a stoma. This included adapting mentally. Karen wasn't fully aware of the toll things had had on her mental health until, when on a visit to the stoma clinic about a problem with leaks, she was asked if she would like to see a psychiatrist. She declined, but says it gave her the jolt she needed. From then on, she started to better accommodate and come to terms with a stoma in her life. She says that this was helped by knowing that, as she had undergone a Hartmann's procedure, a reversal was possible.

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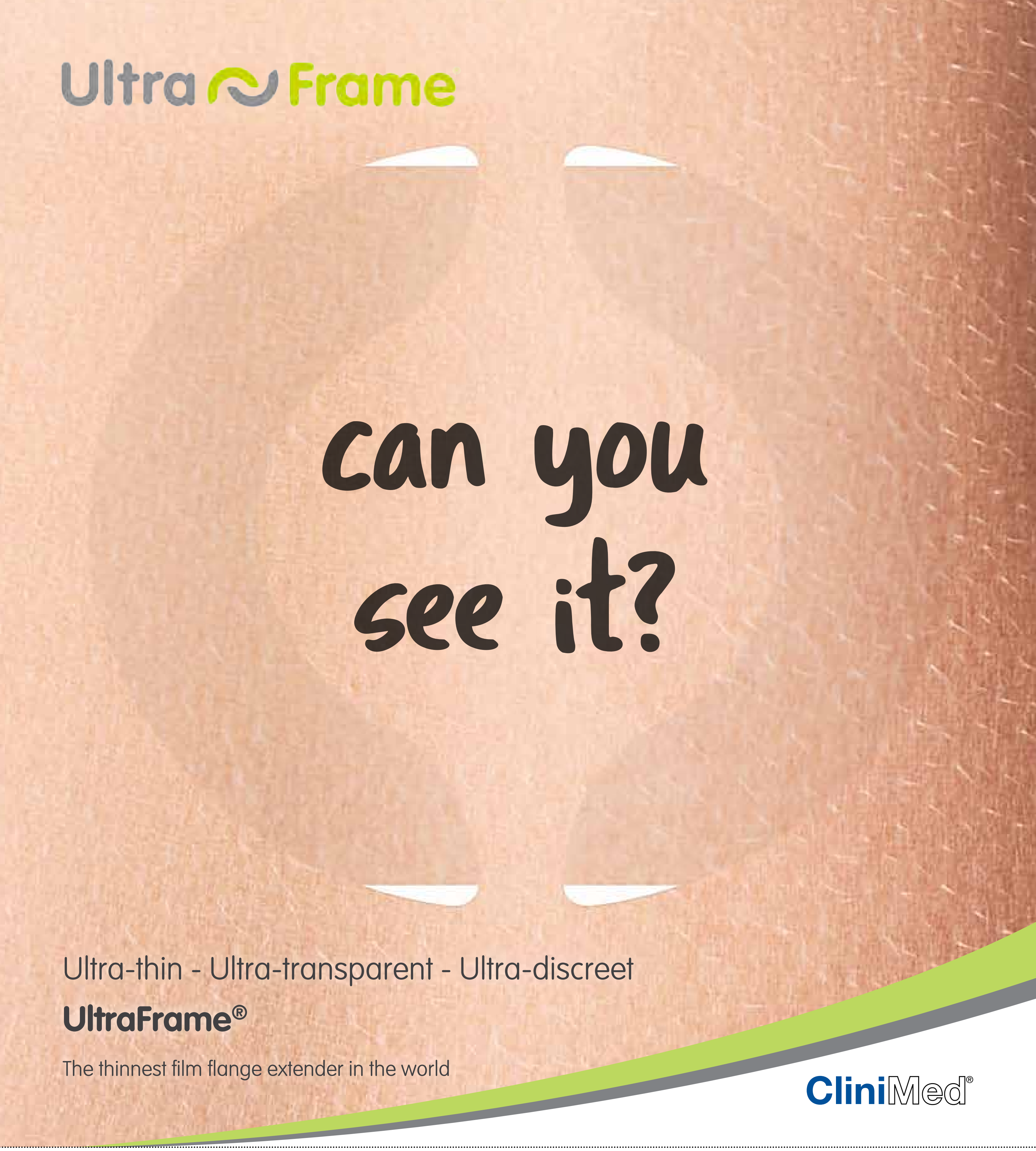
can you
see it?

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Just over a year later, Karen went in for hernia repair surgery and it was around this time that her surgeon started to talk about a reversal. He explained that a temporary ileostomy might be necessary prior to the reversal being completed, but he wouldn't know for sure until he opened her up. Karen went for her reversal surgery in April 2019 and, as her surgeon had warned her, it proved necessary to form a temporary ileostomy. This was because he wanted to repair some adhesions, which meant Karen's insides would then need time to heal before the reversal could be completed. Karen therefore had a period of 13 months in which she swapped her colostomy for an ileostomy. When I asked Karen what was different, she responded that for her there was very little difference at all. She was still able to eat the same things and, with both types of stoma, she felt generally well. She commented that her output was looser with her ileostomy, which in turn meant she had to pay more attention to keeping on top of skin issues. Here she found skin powder and barrier sprays very useful. Beyond this, the only significant difference was in the location of her ileostomy compared to her colostomy. This took a little getting used to.

As I explained at the beginning, when I spoke to Karen, she was well on the way to recovering from her reversal. She was obviously very pleased to be in this position, but wanted to point out that having lived as long as she had with a stoma, she had reached the point where if a reversal had not been possible, she would have been quite content to carry on as she was. This was obviously the exact opposite to how she felt in the early days, when the possibility of a reversal provided her with such solace. When I asked Karen what she thought was the reason for this change of heart, she was able to reply immediately. In essence, once she had recovered from the Hartmann's procedure and been through the process of coming to terms with and accepting her stoma, she quickly came to realise the benefits it brought. In her words, she got back her 'quality of life'. Indeed, the key motivation behind Karen wanting to share her story, was to let people in those early and difficult days know that in time things will get better.

written by Richard Biddle

Editor: Our second story is from Sue Hatton. Sue has been an ostomate now for well over two decades and if you have ever called the Colostomy UK stoma helpline, then there is a good chance you will have spoken to her. Sue is one of our long–standing volunteers. When we changed from the British Colostomy Association to the Colostomy Association in 2005, Sue was the chairperson of the newly formed charity, before going to do a stint as an executive trustee. As you will read, Sue had her colostomy changed to an ileostomy for very different reasons to Karen. She also didn't find the change as easy to start with.

Sue's story

Sue Hatton

I was diagnosed with bowel cancer when I was 46 years old. Treatment began with chemotherapy and radiotherapy. I endured this, along with humiliating incontinence for almost year, by the end of which I was more than ready to have a stoma and regain control of my bowels.

I was referred to Prof Bill Heald, who at the time was a consultant colorectal surgeon in Basingstoke Hospital. Older readers may recognise Bill's name. He was president of the then Colostomy Association before Ian Daniels took over in 2014. In December 1997 Bill conducted my surgery which, as well as a colostomy, included a full hysterectomy. Six weeks later when I returned to have the stents removed, I was taught to irrigate. This set me up well for the years ahead. Even though I can no longer irrigate myself, I remain a passionate advocate of this form of stoma management.

I never really looked back after this surgery until a routine two–year colonoscopy 11 years later, showed polyps in my bowel. My colorectal surgeon at the time bluntly told me that I should have an ileostomy. Horrified and upset I sought a second opinion, which confirmed that I didn't really have a choice. In June 2012 I reluctantly booked into hospital for the surgery. Ileostomies are normally formed on the right–hand side of your body. But my surgeon felt it was better to form it where my colostomy was sited. As I was 61 years old at the time, he did this to reduce the likelihood of me subsequently developing a hernia. Post–op I made a good recovery and my new stoma functioned well. The results of the biopsy showed there was no cancer, which was a huge relief. I saw the stoma care nurses who discussed how the consistency and frequency of output would change. After six days I was discharged with a supply of drainable bags and can honestly say that I didn't shed a tear for my old way of life.

However, three days later my new stoma began to look a bit dark and wrinkly and appeared to shrink back inside. My skin also became very sore. In hindsight I should have called the stoma nurse earlier. When she visited, she insisted that I was immediately admitted to hospital. Further surgery was necessary. The operation to reform my stoma lasted six hours, largely because the surgeon had first to wade through a mass of adhesions. The surgeon was able to bring it out through the same opening again and it was a nice, neat, healthy looking stoma. However, I had a bumpy ride ahead of me as my bowel did not like being mucked about with and went into 'ileus', a state of paralysis. I was very poorly and anything I ate or drank made me sick. Consequently, I was put on a Hickman line and fed intravenously. I spent a total of six months in hospital before finally going home with the Hickman line still in place – so no food! Eventually though, my bowels started working properly again. I was able to introduce small amounts of food to my diet and the Hickman line was removed. I was happy and my husband was happy, as our cottage no longer looked like a hospital pharmacy!

So, what is life like with an ileostomy as opposed to a colostomy? First off, I can no longer irrigate. I now wear drainable bags too. I find that my ileostomy is on the go most of the time and so I have to empty my bag as many as ten times a day (three during the night). I am an advocate of folded puppy training pads which I slot between my stoma and knickers – a life saver! I have always had something of a 'stressy' tummy, particularly when I'm out of my comfort zone, but in the early days with my ileostomy this seemed accentuated. I still remember a train journey back from a Colostomy Association trustees' meeting in Reading and feeling my bag come away, but unable to do much about it as I was hemmed into a busy compartment.

But don't let any of this frighten you. In the end my colostomy and then my ileostomy saved my life. The latter gurgles more than my colostomy used to (stoma symphony, my husband calls it!!), but in all honesty there is very little difference living with either type of stoma. The trials and tribulations are very similar and the effects on you mentally are the same. In the end, like all things, you get used to it. And after 22 years with a stoma (colostomy or ileostomy!) I think I have just about cracked it. ■


SUPORTX
SUPORTX

Dear nurse

Stomal bleeding

Mark Johnson

Clinical Nurse Specialist – Stoma
Fittleworth Medical Ltd

Formation of a stoma brings with it many challenges. Some of these challenges can cause more worry than others. During my time as a stoma care nurse specialist one of the questions that is asked most frequently is why does my stoma bleed and how do I stop it? In this 'questions and answers' I will talk to you about the reasons and possible treatments for it, if and when it occurs.

Why does my stoma bleed?

Whatever type of stoma you have (colostomy, ileostomy or urostomy), the mucosa or pink part that protrudes or is visible is made up using a piece of your internal bowel. When we digest food, the nutrients and fluid are absorbed into our body via our bowel. Because of this the bowel itself needs a large and continuous blood supply and there are many blood vessels that supply it. These blood vessels and their proximity to the surface of the bowel is what gives our insides and indeed the stoma its colour.

Because our bowel moves fairly freely inside us and is able to expand and contract to move food along, it is also very soft, squidgy, and easy to make bleed.

What causes my stoma to bleed and what can I do about it?

There are many causes of stomal bleeding, most of them are nothing to worry about and perfectly normal reactions.

- **Cleaning:** when cleaning the stoma during pouch changes, rubbing the mucosa excessively or roughly can cause blood spotting on the cloth. Most of the time this will stop very quickly on its own, however if it doesn't, applying light pressure, stoma powder or a cold cloth will usually help to stop the bleeding.
- **Rubbing or knocking:** most stomas protrude from the skin, some more than others, and they are very easy to knock, rub or catch on clothing or during an activity that we are doing. Wearing a car seat belt for example can be a very common cause. Try to be mindful of the stoma when doing activities or even when applying the pouch, as the flange can rub when applying down to the skin.
    - If rubbing or bruising of the skin occurs apply some stoma powder or a cold cloth to the area. This will soothe and heal the area. Powder may need to be applied for a few days.
    - Try to find the cause of the rubbing/knocking and, if possible, minimise this. It may be that you could wear different clothing or guard the stoma with your hand. There are some guards and shields that can be fitted with a belt to protect the stoma from sports impacts.
- **Medication:** some medication like blood thinners can cause the stoma to bleed more easily or for longer. If this occurs and the tips above regarding light pressure, powder or a cold cloth don't work you may need to discuss with your GP if your medication can be changed. Your stoma nurse may also be able to advise you.
- **Varices:** this is when a vein of the bowel can come to the surface and be visible. They are most commonly picked up by your stoma nurse but can also become apparent when they start bleeding. Again: stoma powder; light pressure; and/or a cold cloth should be enough to stop the bleeding. If these continue please contact your stoma nurse who may provide further advice and treatment options.
- **Badly fitting pouch or wrong template size:** sometimes even the pouch can cause bleeding of the stoma. Always make sure your pouch is well fitting and the template is correct to the size of the stoma. The flange should not sit on the mucosa and should sit around and protect the skin. If you feel the template is wrong, follow the advice given to you by your stoma nurse regarding template resizing or contact them for information. If bleeding occurs or the flange is cutting into your stoma please follow the tips regarding stoma powder, cold cloth or light pressure.
- **Granulomas:** these can occur on the stoma surface or on the join between the stoma and skin. They are usually small in nature and start as a raised overgrowth of tissue. If allowed to continue to grow sometimes they can form stalks and sit away from the surface. They can bleed easily and can become problematic. As a temporary measure treatment can be as listed already, but these need to be reviewed and treated by your stoma care team.

Stoma bleeding can be very common and the cause usually easily identifiable and rectifiable. But on rare occasions you may need to seek medical attention.

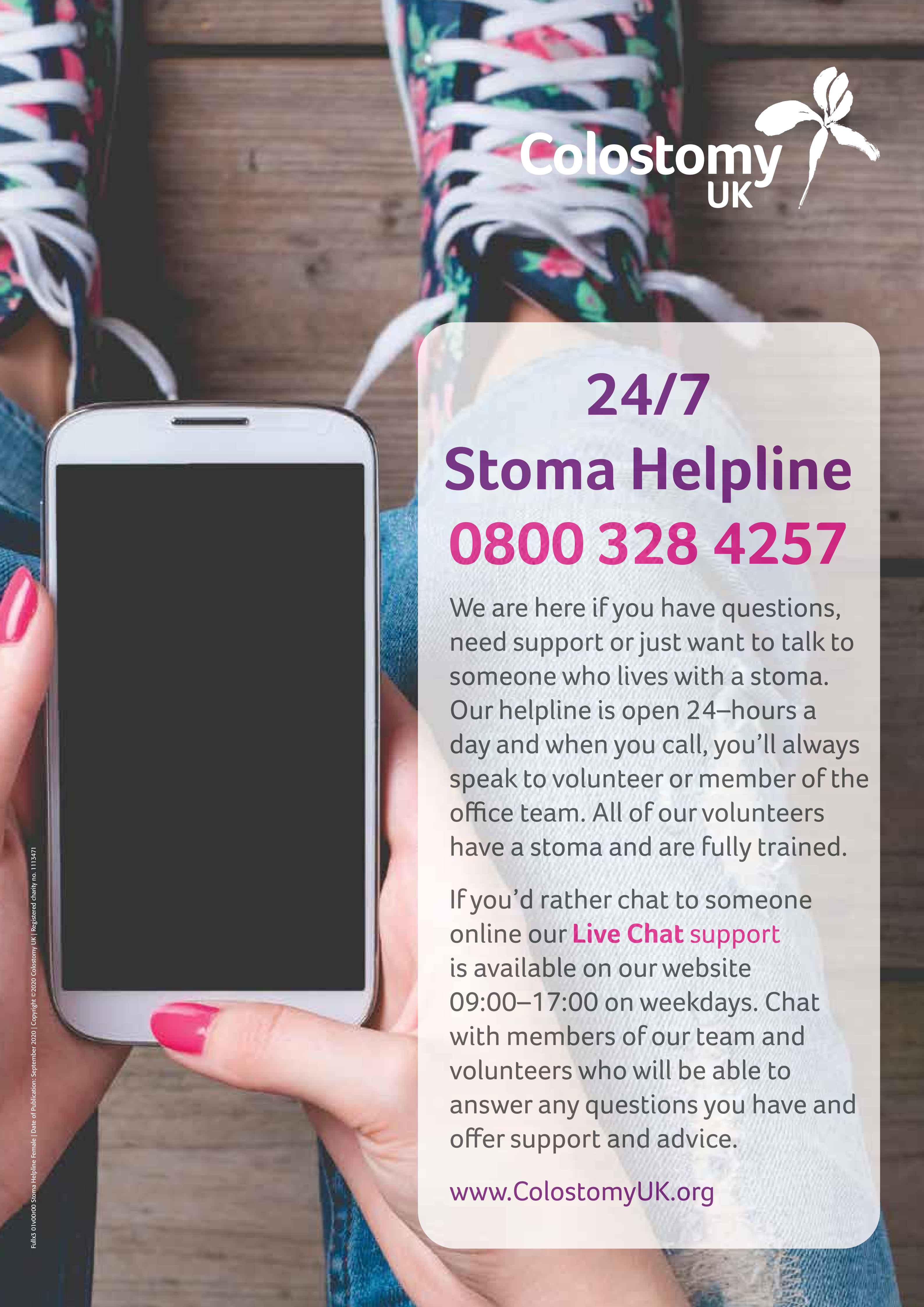
My advice is always get to know your stoma and your routine, find what's normal for you, and then if the unexpected occurs you can usually spot it more easily.

If you are worried, concerned, the bleeding is excessive or you notice blood in your stool or urine, during office hours (and these will vary by department) your stoma nurse should be consulted. If outside of these hours or they are unavailable you should consult your GP, NHS 111 or in urgent cases your local A&E department.

Stomal bleeding can be distressing, especially if it occurs unexpectedly. But your local stoma care team or nurse are on hand to offer help, tips, advice, and treatment to help you come to terms with your stoma and help you to build confidence. They can offer support and help enable you to live the life you want and not let your stoma slow you down!

Accurate stoma template measurement.

An Ileostomy with a mucosal granuloma and a bleeding point. Varices at the base.



Colostomy UK

24/7

Stoma Helpline

0800 328 4257

We are here if you have questions, need support or just want to talk to someone who lives with a stoma. Our helpline is open 24–hours a day and when you call, you'll always speak to volunteer or member of the office team. All of our volunteers have a stoma and are fully trained.

If you'd rather chat to someone online 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 01v00r00 Stoma Helpline Female | Date of Publication: September 2020 | Copyright ©2020 Colostomy UK | Registered charity no. 1113471

Childbirth trauma and stoma surgery: Jo’s story

Joanna Prance

My name is Jo and I’m a new ostomate, having had stoma surgery in December 2019. I am 44 years old and, despite having a healthy bowel, I have spent almost half my life living with bladder and bowel dysfunction. This was the result of traumatic childbirth. As some readers will know, this can damage the anal sphincter complex and/or pelvic nerves. In my case, a colostomy offered a fresh start, after other treatment options had failed to control anal incontinence. By sharing my story, I hope to highlight both the risks and consequences of obstetric anal sphincter injury (OASI). As an ambassador of the MASIC Foundation, (Mothers with Anal Sphincter Injuries in Childbirth) I want to raise awareness of the only UK charity that supports women with these injuries.

The number of women affected is significant. People in general (including healthcare professionals) don’t realise that up to 20% of adult women experience anal incontinence, many of whom will have had a severe perineal tear giving birth.* Many women affected by a birth injury have worsening symptoms around the start of the menopause. Indeed, some who had virtually no trouble after a traumatic delivery, go on to develop new symptoms of poor bowel or bladder control at this time. The exact number who fall into this category is unknown, partly because the taboo surrounding anal incontinence in particular, means very few women feel able to discuss it. This just adds to the physical and mental challenges of living with an inability to control your bowel.

22 years ago, I was induced and experienced a traumatic birth delivering a large baby extremely quickly. This resulted in second degree perineal and vaginal tears, which required extensive stitching. I was 22 years old and the extent of the damage caused by this birth did not become apparent immediately. I was aware that sitting was extremely uncomfortable and swelling from the repair took months to settle, but I was assured this was all normal. I had no idea I had experienced a life–changing injury. Nor was I aware that a future of battling incontinence lay ahead. Like many women I was not educated about the all the risks associated with childbirth.

Prior to having my son, I was an avid exerciser who loved sport and exercise without limitations. I was therefore shocked when, one year after giving birth, I started to suffer urinary stress incontinence. After extensive physiotherapy failed to resolve this, I had a TVT mesh sling inserted. It remedied the urinary incontinence, but I was left with unexplained left–sided pain which became chronic as the years passed. The sling was eventually removed successfully in 2016. Three months after the TVT was inserted, I started to experience episodes of bowel urgency and leakage, which proceeded to get worse. I was absolutely mortified that I could not control my body and was given a combination of medicine to try to manage the symptoms. This anal incontinence didn’t just affect all areas of my life but also my husband’s life and my son’s life, who has grown up alongside my medical journey.

Psychologically, one of the biggest obstacles I faced at first was trying to ascertain why I had these problems. Initially, it was presumed I had IBS or had picked up a virus overseas. It was even insinuated that I had incontinence issues prior to the birth. As the urgency and incontinence increased, I requested a meeting at the hospital where my son was born. The lead consultant’s response was dismissive. I was told my problems would go away in time and that I was psychologically traumatised from the birth and everything was normal. There was no recognition that the birth may itself have been the cause.

The physical symptoms however, persisted. As a result I underwent years of treatments, physiotherapy and rehabilitation, alongside multiple surgeries to remedy bladder and bowel dysfunction. But even with these interventions I still found myself with little control and needing to rush to the loo multiple times in the mornings. Having had limited success with sacral nerve modulation, my surgeon mentioned a colostomy as a possible future option. In his words I was stuck between a rock and a hard place. At the time I found the idea of colostomy terrifying and wasn’t ready to pursue this route. Hence daily rectal irrigation became my solution. Over the years I used several irrigation systems including Qufora, Peristeen, Navina Smart and Qufora IrriSedo Mini. It was while managing my problems in this way that in 2015 an ostomate and good friend had the foresight to get me to attend the SOS

CONTINUED ON PAGE 25, COLUMN 1

Colostomy UK

Looking for online support?

Our private facebook group is a secure and supportive community of over 8,000 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

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CONTINUED FROM PAGE 23, COLUMN 3

stoma support group in Southampton. I found this invaluable. Thanks to the members I learned a lot and suddenly the idea of a stoma wasn't so awful.

Looking back, I appreciate more than ever how important this moment was in terms of easing my fears about having a stoma. In the period that followed the meeting, my symptoms continued to get worse. Eventually, it got to the point where I was needing further irrigation sessions in the afternoon and my life was heavily dictated by needing to be near a toilet; I felt stuck at home. It was then, following a discussion with my now stoma care nurse, that I decided a colostomy might be my best solution.

My surgeon was very understanding. Thanks to his amazingly positive approach, I began to see a colostomy as a new beginning rather than a last resort. As this was my 17th surgery, it meant a lot to me to hear him speak in these terms. I went to theatre with a positive attitude. I elected to have a Hartmann's procedure. I wanted some assurance that if things didn't work out, my stoma could be reversed. Involving my husband in the decision–making process was hugely important as this was going to be a big adjustment for both of us. By commenting on how stomas looked like sea anemones, he unintentionally named my stoma…'Anemone' has stuck.

Because the surgery was planned, I had time to prepare for life with a stoma. Beforehand I researched and experimented with different bags and stoma support garments. I wore them as much as possible and I made changes to my swim wear. This was vital to me as swimming is one of my main forms of exercise. Being extremely active, these modifications along with all I learnt prior to the surgery was invaluable afterwards. Post–op it helped me to adjust quickly and gave me the confidence to return quickly to exercise. I was swimming again in just six weeks! I know that recovery times from stoma surgery vary from person to person. I was lucky. I had just one setback four weeks post–op. I felt nauseous and had headaches I couldn't shift. Then I was violently sick and I was admitted to hospital. Initially it was thought I had a blockage but it turned out to be a sodium issue and following a fluid restriction I started to feel better. Since then I have felt fine. Overall, I would say my recuperation was straightforward and not painful, which was a pleasant surprise, after some of my other surgeries!

My Hartmann's was performed two weeks before Christmas and before the new year we took a family trip to the coast. After a great walk along the beach I had my first meal out and as the winter sun set, I felt like I had been given a new lease of life. Recently, I returned to the beach this time wearing a bikini and one of the many pouch covers I have acquired. Free of the anal incontinence, my confidence is much restored. Anemone has given me back my freedom. In my husband's words, I am more like me again.

I now realise the second–degree tear that I was informed had occurred was in fact a third–degree tear. If this had been identified and repaired when my son was born, it could have prevented the bowel issues that I had to live with for two decades. I have not allowed what happened to define me. Apart from a short break in 2016 (when I needed multiple surgeries) I have continued to work as a personal trainer. When I first qualified, I taught cardiac rehabilitation. In my twelve years as a specialist instructor I met people of all ages and with a variety of health conditions, some complex. After 2016, the experience of having to rebuild and restart my journey back to fitness after each surgery, prompted me to take a new direction. Realising that my career as an instructor wasn't over I undertook a fitness pelvic floor course. Combined with my own experience and knowledge gained from living with pelvic floor dysfunction, I now help other women to achieve their goals.

MASIC

Mothers with Anal Sphincter Injuries in Childbirth

If you have suffered the consequences of OASI or perhaps know someone who has, please let them know about the MASIC Foundation. Although it is a new charity, it already has 150 mothers who are suffering from the condition, and who are willing to talk to others about it. Social media is helping MASIC to increase the numbers of women it supports too. Importantly, MASIC is also campaigning for better information about risk in pregnancy and better detection of injuries so they can be repaired at birth as well as primary prevention of them too. In collaboration with the Royal College of Obstetricians and Gynaecologists and the Royal College of Midwives, MASIC is putting together the OASI Care Bundle to reduce the risks of these injuries.

Ed's note: The MASIC Foundation (https://masic.org.uk/) can be contacted on 0115 937 5934. You can also e–mail them: admin@masic.org.uk 🟩

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[*] Gray, T G, et al, *A systematic review of non–invasive modalities used to identify women with anal incontinence symptoms after childbirth*, International Urogynecology Journal, Nov 2018.

Jo with her son on her first trip to the beach after stoma surgery.

Crossing the line

Chris Morrison

After three gruelling days in the Sahara, Chris Morrison used his heel to draw a line in the sand. With no official finish, he and his trekking partner felt they should cross something to mark the end of an incredible journey. But as Chris stepped across, something happened. The memories of what he and his family had been through came flooding back. No longer was it a simple finish line. Instead, it was the proverbial 'line in the sand': a moment of going forward, embracing the future and never looking back.

When I interviewed Chris back in January, he was a few months post trek, and enjoying life as a newly promoted Operational Watch Commander with Northern Ireland Fire and Rescue Service. Having been a firefighter before, he is now in charge of a 12–man watch. It is a demanding role he says, especially around Christmas and the bonfire season when things can get very busy! It wasn't that long ago though, that Chris was at home recovering from stoma surgery and wondering whether he would ever get back to fighting fires…

In the summer of 2016, Chris started to experience rectal bleeding. His GP initially diagnosed haemorrhoids, but as summer moved to autumn Chris' problems continued. This led to a hospital referral in October, where it was subsequently found he had a tumour. Because of its location in the bowel, a permanent colostomy was Chris' only treatment option. Six weeks later he underwent stoma surgery and had the tumour removed. Thankfully it proved to be benign, but there were indications that it was changing.

Chris remembers the period as one of mixed emotions. On the one hand, there was relief at the prospect of being treated. In the weeks leading up to surgery he was admitted to hospital on several occasions because of bad bleeds. Indeed, his blood count became so low towards the end that the doctors started to get concerned. On the other hand, Chris had to contend with the shock that accompanies the news you need a colostomy. Chris admits his knowledge of stomas at the time didn't help, being limited to all the old clichés about 'bags' and 'old people'. Chris was also worried about what the future might hold and, specifically, whether he would be able to resume his duties as a firefighter. When his surgeon advised him there was no reason why he shouldn't, it was a great relief. Chris thus set himself the goal: to be back at work within a year.

Chris almost achieved this, returning to active duties just over 12 months later. It seems to me that there is much to be said for focusing on life goals in this way, rather than dwelling on the treatment needed to get you there – if only we were all equipped to adopt such a positive frame of mind in trying times. That's not to say Chris didn't struggle. As he explained, he also had some concerns about going back to work, but ultimately it was the tonic he needed to complete his recovery. His colleagues aided his smooth return. In fact, he says they were supportive to the point of almost being over–protective. Chris was touched by this, but also had to remind people that he needed to be just as active and participate just as hard in things like training as everyone else. Before long he felt almost back to normal, enjoying all the banter that characterises life at a fire station. The only thing that he found difficult was outreach and public engagement work. This required him to give talks at schools and the like. In the early days, his stoma was a bit unpredictable and had a habit of making noises at the most inappropriate times (something I'm sure many reading this article will sympathise with!).

In between his surgery and return, The Firefighters' Charity arranged for Chris to visit their centre in Devon, where he had acupuncture and physiotherapy. It was this and his more general desire to do something tangible to say 'Thank You', that found Chris trekking across the Sahara in late 2019. I asked Chris what made him do it. After all, there are far less strenuous ways to 'give back'. What's wrong, for example, with raising funds for a charity by doing a bike ride? Chris explained that it came about as a result of him scrolling through Facebook, where he saw an advertisement for the trek. What stood out immediately to him was the date: 31 October to

4 November. With these matching his second hospital stay before surgery it seemed that fate was playing a hand. Martina, Chris' wife, thought it was a good idea and so, almost before he knew it, he was signed up, with 10 months to prepare (and worry about if he had made the right decision)!

The adventure began with a flight from London Gatwick to Marrakech and was followed by a frightening six–hour drive on the treacherous roads that snake their way across the Atlas Mountains. Many a time Chris regretted looking out of the car window and over the edge. The first night was spent in the comfort of an hotel, before another four–hour drive in the Atlas Mountains which took them to the start point. Here the minibus was unloaded and the caravan formed. It comprised 23 trekkers, camels for their luggage and service camels that carried extra supplies of water. Each trekker had their own personal backpack and a two–litre water bladder. Ahead of them travelled (by van) a team who set up the tents at the night's stop and did all the cooking. Chris said that seeing the van in the distance after a hard day's trekking was a great motivator. Not only did it signify a well–earned rest, but also some grub! Chris says that everyone marvelled at how the cooks were able to make such good food in the desert conditions; they even baked bread and roasted chickens.

The trek lasted three days, much of which was spent walking on what Chris described as a lunar landscape of wide expanses littered with rocks. I assumed that deserts were just sand and more sand, but apparently not. Chris said that the Sahara is in fact only 20% sand, with the rest being the rocky terrain they traversed. They also walked along a dried–up riverbed, where the mud had cracked like an Easter egg. Weatherwise, daytime temperatures never dropped below the 30s, which was a challenge given the rugged nature of the terrain. At night, they had been warned that temperatures could drop below zero, but this didn't happen. Chris said that without any light pollution the starry sky was a spectacular sight to behold (and fall asleep under!).

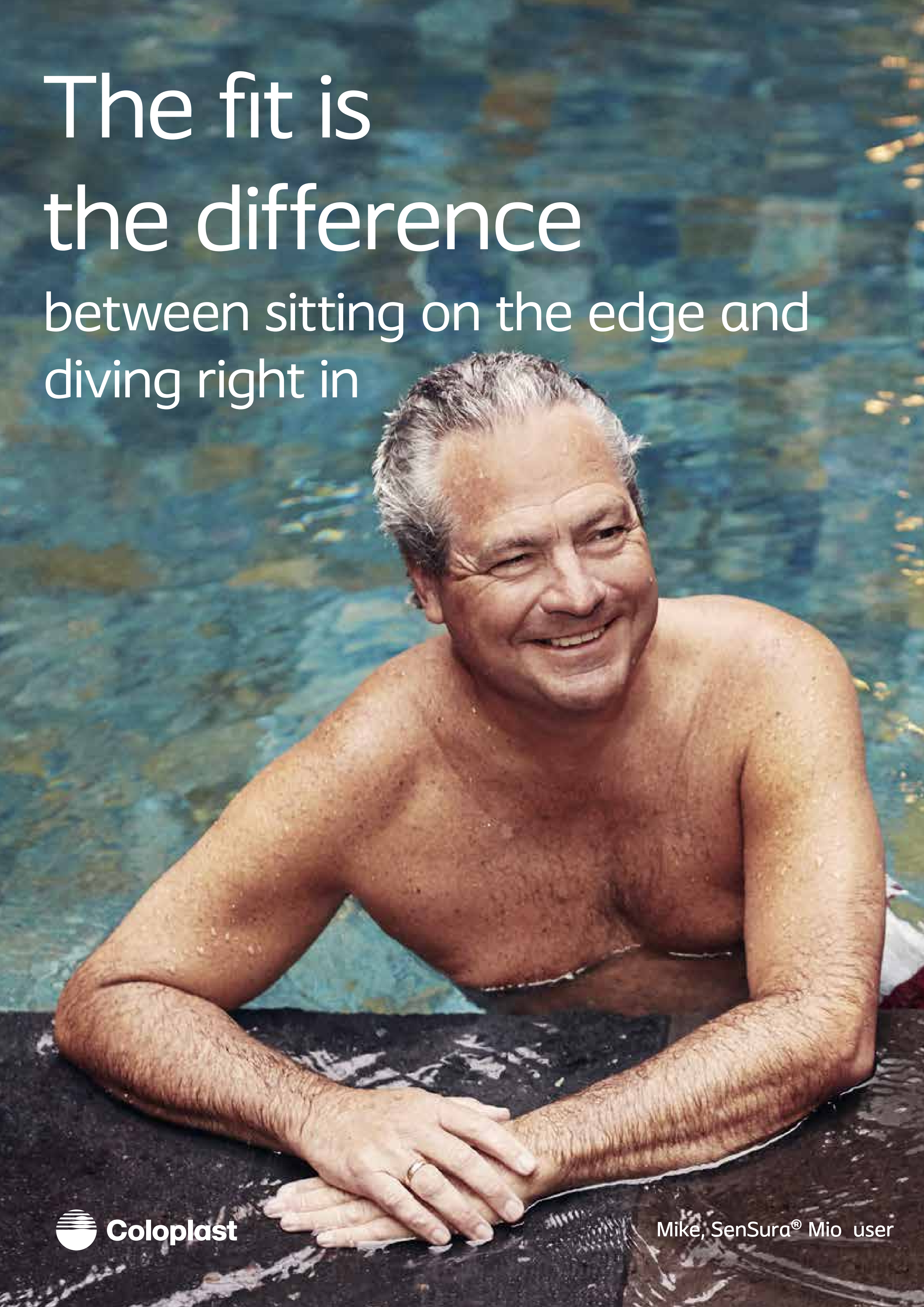
So how did Chris fare as an ostomate in such a hostile and unforgiving environment? The simple answer is very well. Toilets were a hole in the ground and, amusingly, the other trekkers were envious of Chris as he didn't have to use these 'facilities'. On a recent trip to France the heat had led to problems with bag adhesion, but Chris didn't experience this while he was in the desert. His worries about getting sand on his stoma (in case it rubbed), proved unfounded. He also managed bag changes without issue. With so many rocks around, it was easy to find one suitable to go behind, lay out his supplies (he took a month's worth) and change. Likewise, staying hydrated wasn't a problem. At the back of his mind was the concern about what would happen if he got a blockage or needed medical assistance but, as he said, you can't let fears like this get a grip, otherwise you'd do nothing. Chris explained that once he set off each day and got talking with the other trekkers (many of whom were fundraising for good causes and had incredible stories of their own) he forgot all about his stoma. He thinks his wife ended up worrying more than him.

Chris says that the trek was physically and mentally challenging and he has over 900 photographs to prove it! For him though, the last day and crossing that line in the sand will always be an overriding memory. It made him think back to where he had been just a few years before, how far he had come since, and all the people who had helped and supported him on the way. As he said, it is because of his stoma that he is still able to do the job he loves. I hope people can draw inspiration from Chris' story, particularly those whose stoma journey has only just begun. It will get better, and while not everyone is destined to become Lawrence of Arabia, what Chris did supports the view that having a stoma need not be a barrier to life.

written by: **Richard Biddle**

The fit is the difference

between sitting on the edge and diving right in



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My Stoma Story

Jo Easterbrook

Editor's note: I am very interested in the therapeutic value of writing. Writing helps me order my thoughts, reflect on things and has, on occasion, made it easier for me to come to terms with difficult experiences. Members of the **Colostomy UK** private Facebook group will probably recognise the author of the article below. Just like me, she has a passion for writing and uses prose and poetry to record life's moments. She put her talents to good use following her stoma surgery in 2016. What follows is at turns serious, sad and humorous. It is a raw exposé of a person reacting to the news of needing a stoma and their subsequent surgery and hospital stay. Ultimately, it is life affirming and, as you will see, finishes with some great advice for people at the beginning of their stoma journey.

In 2016 I noticed poo coming from my vagina. This went on for several months. Well that's not your normal everyday occurrence so I was sent for investigative tests.

Four messy months later I attended a meeting to discover the 'verdict'. The surgeon told me I had diverticular disease and a colovaginal fistula caused by an abscess, that would necessitate removing the offending part of my large bowel. Shocked into a state of 'zombieism', I listened as he explained I would have to have a colostomy and, because of my previous surgeries, my colostomy would be permanent. My first thought was: is it April Fool's Day? Was this his idea of a joke? Once the surgeon had finished delivering his 'who can I upset today' speech, the revelation set off a bizarre process within me. My stunned brain called all systems to shut down: heart went into overdrive and pumped so loudly that my ears nearly bled; bowels decided to go south huffing and puffing for England; eyes were out on stalks distorting the surgeon's face; lungs thought they had run a marathon and limbs acted like they had had an alcohol overdose. I turned to my husband for the kiss of life but he was in suspended animation. How could one man's words have had so much power over my body and mind? Would I soon awaken from this nightmare? Had I morphed into Alice In Wonderland and slipped down a rabbit hole into a world of fantasy?

The go ahead for surgery was complicated by my past medical history. This led to some delay and left an already anxious me not knowing whether to laugh or cry. Eventually I was declared fit for surgery. Oh! Shit! I thought, it's really going to happen – excuse the pun. Shortly afterwards, feeling like Paddington Bear with my little red bag, I RELUCTANTLY turned up to the nurse station. I still don't know why I smiled at her when my legs were in flight mode.

Here are some entries from my journal:

Day before surgery

Everyone is so sweet and welcoming. I wonder if they know something I don't? Could it be guilt for starving me? Nurse 'Dread' came at me armed with a tube full of something that looked like milky water. She told me to lie on the bed and lulled me into a false sense of security – then she shot the tube so far up my rectum I thought she was performing a tonsillectomy. 'Hold it as long as you can', she said smiling sweetly, 'then run!'. Second time nurse 'Dread' came anus muscles refused to succumb without a fight. What kind of a person believes their victim could relax whilst being tortured – a nice hot bath does that, NOT, a cold poker up the jacksie!

Day of Operation

I was in the anti-room pre-operation. I 'felt' like a lamb to the slaughter but in truth they were saving my life. I think the staff thought it was a party, laughing and joking amongst themselves inviting me to join in. REALLY?

A happy person smiles at me and sticks a needle into my hand saying: 'just a small scratch'. Not! A few expletives came to mind which thankfully didn't get past the lips. Then another 'small scratch' into the artery! I had imagined that I would be asleep before I went into the 'torture chamber'.

'Sit up', said the anaesthetist. Sit up? I've just been stapled to the bed and he wants me to sit up! So 'obedient' brain did as it was told, without question; I blame my upbringing for that. 'We need to put a line into your spine,' whilst I'm thinking, 'you swine'. Umm poetic! "Cool spray" said the jolly nurse spraying ice up my back. In went the needle containing 'slow acting' local anaesthetic and before it had time to act the line was pushed in. I prayed, maybe for the first time in years. I prayed for unconsciousness, but nobody inside wanted to be responsible, not even 'obedient' brain. Back to the anaesthetist who really should've been a butcher and who I will now refer to as 'The Grim Reaper', makes yet another attempt to enter my back with his 'line' catching the spinal nerve in the process. This line is supposed to be a means of getting morphine into my back post-op via a release button. By now though, I was telling him to abort and that paracetamol would do nicely, thanks.

pto

FOOTER ITEM 1 FOOTER ITEM 2 FOOTER ITEM 3

Finally, 'God' came to save me saying, 'We will now put you to sleep'. Thank the Lord! Three and a half hours later I was startled awake by heart rebelling so much, so I thought I was dying. Huh! Not only was heart getting its own back, but lungs were flatly refusing to inhale.

Five minutes later it was all over.

No, not my life!!! The operation!!

Day One

A blur. I sensed it was busy cos I didn't have time to sleep. A couple of 'Florence Nightingales' – my little angels were keeping watch over me.

Day Two

Ordered out of bed by someone purporting to be a nurse. Said she couldn't help as she had a bad back! What!! With an eight-inch cut up my tum I somehow had to command muscles, who were sulking with me, to pull my body out of bed. I managed it but, most importantly, the nurse's back is OK!

Day Eight

Looks as though I can go home! There I was preparing my escape complete with 20 self-administering injections and a sharps box. Ha! Some goody bag eh? Thought I had my get-out-of-jail free card! Except… turned out there was a good behaviour clause. I had to first pass the competency test: take off and replace stoma bag. Easy peasy me thinks. I am a member of Mensa after all!

FOOTER ITEM 1 FOOTER ITEM 2 FOOTER ITEM 3

With stoma nurse sitting snugly between my legs she coaxes me to use a lovely mint smelling spray and a willing hand to tease the bag off; so far so good. A couple of sprays and it was starting to free itself…and then!!…all my senses took control of my body and brain was almost rendered unconscious. My unsuspecting stomach retched involuntary and just before I lost it, I caught sight of the fear in the nurse's eyes. She braced herself for a vomit shower, which thank God refused to exit. I can't begin to explain the sight of a little, brown foetus looking thing disappearing out of my belly and into a bag. This was all too much for the eyes who promptly shut and refused to open. 'Look at IT!' an anxious voice demanded where upon another involuntary reflux came forth with threatening veracity. 'OK' the shaky voice of the nurse said…'I'll do it this time!'

That cost me a night in solitary. How I'm going to con myself into doing the necessary beats me. I'm certainly not going to use minty toothpaste again and nose has lost trust for ever.

Day Nine

Well after fitful sleep I gave myself a stern talking to but, once again, stomach decided on mutiny. Then it happened, face joined forces with tummy and attracted a sympathetic response from the person in the opposite bed. She was in a similar situation A bit of sympathy and heart triggered eyes again…another 20-minute eye shower and the new 'Angel friend' floated back to bed, also with flooded eyes! An hour later still no sign of the stoma nurse who I now think of as the 'Angel of Death'.

pto

FOOTER ITEM 1 FOOTER ITEM 2 FOOTER ITEM 3

Three hours later and after 'floaty angel friend' had given me loads of advice, I was getting some momentum to 'do it' myself. Aha! Get out of jail free card was getting closer! 6pm Angel of death had escaped without a visit leaving me boiling. Another bloody day lost!

OMG!!!!!!Then it happened…The Hulk turned up, aka 'my alter ego'. Turning green with rage at Angel of Death's absence, "Right you lot"! Alter Ego shouted: "we will show her! How dare she bottle out: we can do without her!"

New floaty angel friend, new nurse and I got to it. This time new angel friend sat between my legs with an encouraging brave look on her face, encouraging me to do it. Imagine someone giving birth and eager unblinking eyes straining to see that which was about to be born! YES!! dear reader you read that right! Geronimo!!!!!

How did I do it? Alter ego was so damned angry that all the senses and organs were scared shitless and dared not rebel. Can't believe I just said 'shitless'!

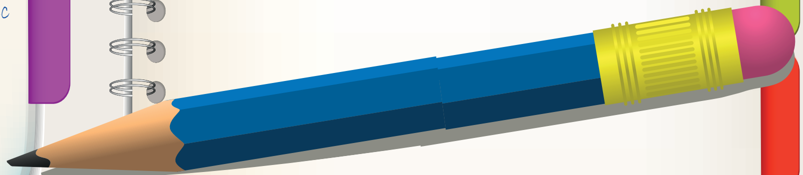
Dry eyed and full of pride I awarded my new friend a badge which I proudly pinned onto her NHS-issue nighty….A stoma bag!!!! Well what did you expect, we were in a hospital.

FOOTER ITEM 1 FOOTER ITEM 2 FOOTER ITEM 3

Can't wait for tomorrow when Angel of Death turns up.

Day Ten

Angel of Death honoured me with a visit, smiling, so clearly suffering from amnesia. "Too late, I already did it!!" I said, proudly. Looking more put out than relieved she wanted to see a repeat performance of the night before. I don't think she believed me. Anyway, Angel of Death grudgingly agreed I had done an ok job, so I forgave her. I liked her really;-).



Finally, home I went

Here are my tips with a little input from members of my support group and the **Colostomy UK** private Facebook group:

1 Hold on to the fact that whilst your operation wasn't something you chose, it is a life saver.
2 Remember, after bowel surgery you will be traumatised. Bowels do not like to be handled.
3 Some get almost instant benefits, some don't.
4 You will take months to recover physically and emotionally. Don't worry if you think you aren't doing it quick enough.
5 Nothing is going to happen in a hurry, except output .
6 You will cry; it's part of the process. Let it out.
7 You are not born an expert in 'stomas' you have to learn.
8 Output varies day to day. You will learn about diet through your nurse, the internet and experience. We are all different. Keep a food, alcohol and medicine/health supplements diary. It will help work out which foods your body reacts to. Alcohol especially, affects output!
10 All bags are different. Try them all until you get the right one for you. You can also get aids to help with the leaks.
11 Stomas can get sore and there are products to help.
12 Take care with lifting and straining. You don't want a hernia. You can get support wear. When your nurse gives you the ok, try some core strengthening exercises but make sure they are ones for ostomates!
14 Find out about irrigation.
15 You will have accidents, its normal and you will learn how to manage.
16 You can live a normal life once you get used to your situation.
17 You may still have an instinct to push. Mucus collects in the anus and once it is released you will feel better.
18 Blame windy noises on the dog. If you don't have a dog and your partner won't take the blame say it was your ring tone. If all else fails, be brave and own up;–)

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Stomas and dementia

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

Having a stoma can take a period of adjustment. Some people report that they never truly adjust to life with a stoma. Having dementia is a changeable condition that can complicate life with a stoma. This article explores both issues and offers some practical tips that might be useful for people with dementia and a stoma.

What is dementia?

Dementia is a physical condition that arises due to changes in the brain structure. The most common types of dementia in the UK are Alzheimer's disease and vascular dementia. Most dementia will develop gradually. Dementia is the result of changed communication pathways, as a result of damage to the nerves within the brain or blood supply to the brain. Thus, depending on which part of the brain is damaged this will relate to the specific symptoms for the individual.

Who gets dementia?

People over 65 years of age are more likely to get dementia than younger people, but it can occur at ages much younger than this. Dementia is common, with about 1 in 70 people having dementia and these numbers are likely to increase as the population ages. It is thought that by keeping healthy and active dementia can be delayed or prevented.

How does dementia affect people?

Dementia often affects the memory, particularly short–term memory. New information is difficult to retain. Additionally, where items have been placed might be forgotten, thus people with dementia might regularly misplace their belongings. Other people lose sense of time and place. They may get lost in places they know, whereas other people with dementia may wander. For some people they might forget names or repeat themselves. For others reading and writing can be difficult. Decision making may be impaired, which can put them at risk. People may seem to have a personality change, becoming less interested in their usual activities. Sometimes it is not an easy task to diagnose dementia as we can all forget things and symptoms are often gradual. Sometimes symptoms can be similar to other conditions such as depression or infections in the older person. There are specialist services available for help, such as Admiral Nurses, which can be accessed via the GP once a diagnosis has been made.

Dementia and stomas

Having dementia can negatively affect the ability to care for a stoma; some people might not be able to be independent with their stoma care. That said, wherever possible it is useful to encourage as much participation with the stoma as the person with dementia is able to undertake. Repetition can assist the person to be reminded about caring for their stoma.

It is useful every year to have a stoma nurse review the person with a stoma, the stoma and the appliances. It is important to ensure that stoma products are the most appropriate to use. The stoma nurse runs clinics. Some stoma services are also able to offer home visits if people are housebound, so it is worth checking whether community support is available locally. The review might include a check of the stoma size, which may alter slightly over time as a result of changes in weight for example. It is important to ensure that stoma supplies are regularly ordered so that they do not run out or become stockpiled. Adding reminders to the calendar or setting up regular deliveries can be useful.

For people able to perform their stoma care with some assistance, there are a number of potential things that may be helpful. Having written instructions or images of how to change the appliance in the bathroom can be useful as a reminder.

For other people a pre–packed stoma appliance change kit can be useful. Instead of collecting each item from larger supplies, it can

CONTINUED ON PAGE 35, COLUMN 1

Colostomy
UK

WHY join us?

As a registered supporter of **Colostomy UK** you will receive a welcome pack full of useful information.
Each quarter you will also receive a copy of this award winning magazine called *Tidings,* and much more…

- Access to the latest stoma product updates.
- The latest news and views from **Colostomy UK** direct to your inbox.
- The option to take part in surveys and have your say on the future of stoma care in the UK.
- Help us be the voice of ostomates.
- Access to our support literature and factsheets about all aspects of living with a stoma.

Joining is free and friends and family are welcome to join too.
www.ColostomyUK.org/join-us/

Fullx3 01v01r00 Why join us | Date of Publication: December 2020 | | Registered charity no. 1113471

CONTINUED FROM PAGE 33, COLUMN 3

be helpful if all the equipment that is needed for one appliance change is placed together. Thus the carer can put cleaning wipes and a clean appliance into a waste bag ready in advance of the appliance change.

Some people with dementia 'fiddle' with their stoma appliance, which can result in appliance leaks. There are a number of ways in which access to 'fiddle' with appliances can be reduced. Using a stoma belt can assist the appliance to be more firmly held onto the abdominal wall. Covering the appliance with large underpants or tucking vests into underpants can also be beneficial. Some people have tried mittens, to reduce manual dexterity. Fiddling with the appliance might occur when the appliance is full and heavy. Thus it is important to ensure stoma appliances are changed when required. A stoma appliance should be changed when a third to half full. It is also worth considering that there might be irritated skin under the appliance. To prevent skin irritation ensure that a suitable change routine is maintained.

For people unable to care for their stoma, a carer will be needed. Some people are happy for carers to change appliances for them. Others may try to touch the stoma while the appliance is being changed. In this situation it can be helpful to try and distract the person so that they focus on other activities.

Summary

It can be seen that caring for a stoma when the person concerned has dementia is potentially difficult. Memory issues may mean that people forget what to do and when. This can include ordering new products or the way in which to replace an appliance. Help is available from the specialist stoma care nurse or Admiral nurse (specialist dementia nurses who work for Dementia UK). ■

At Colostomy UK we recognise that caring for an ostomate who develops dementia or caring for a person with dementia who goes on to have stoma surgery, can be challenging.

This is why we have added a new dementia module to our Care Workshops. Delivered in the community, these are aimed at staff in nursing homes and residential homes as well as home carers. To find out more visit our website. In collaboration with Dementia UK we also produce the booklet pictured above. You can download a copy free from our website. Alternatively call us: **0118 939 1537** or e–mail: **Info@ColostomyUK.org** to request a copy.

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:

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.

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 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.

Signature of self or carer:

Date: / /2020

T60

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

Reflections on a life lived with chronic illness

Molly Belding

What an honour to be able to have my words read by so many other awesome chronic illness, IBD and/or stoma warriors! Hi – my name is Molly, I am 28 years old and from Somerset. I love Marmite, dogs, Strictly Come Dancing, my family and being able to live in a beautiful rural part of the world. I have also had Crohn's Disease for 16 years and a permanent colostomy called Neville for eight years.

My life has been an adventure to say the least! You name a medication or surgery and chances are I have had it. If my CV could consist of completed medical procedures… I'd be called an over–achiever!

I'll start with a brief overview to give context to this article. I was diagnosed with Crohn's age 12, out of school for four years due to poor health, and miraculously I re–joined my year group just in time to do my GCSEs, which enabled me to progress to college. I became particularly unwell again in college so had to extend to three years instead of the usual two. I had a year out to have my stoma and then began university for three years to become a paediatric nurse (obviously that didn't go to plan – I had to extend by a few months to have another bowel resection). Currently I work in the Child and Adolescent Mental Health Service. Last year I had a stoma refashioning and resection – just to keep things interesting for 2019!

Throughout all the above events in my life, I was pill–popping and being intravenously infused with lots of different immunosuppressants, steroids and biological therapies to try to gain control over my Crohn's (this worked on/off – anyone with IBD will appreciate the roller–coaster that flare–ups entail).

What I would like to do is reflect on the lessons I have learnt so far in my life:

1) **Never take health for granted**
Health should be everyone's number one priority. As one quote states: 'health is a crown that the healthy wear but only the sick can see'. In the current Covid–19 pandemic, everyone is experiencing a heightened sense of their own mortality and vulnerability. We, IBD/chronic health pros experience this feeling frequently with musings such as 'What long–term effects will my current/past medications/surgeries have on my health?' Decisions that were made when we were newly diagnosed could potentially impact our future health outcomes.

2) **Trust yourself**
It is you and only you who will be dealing with your IBD/chronic illness for life. I vividly recall one night over a Christmas period in hospital, I was the only one in the bay and I heard hospital volunteers singing carols. That memory clings to me; a moment when I realised I was on my own – not alone (my family are amazing) but that ultimately I would be the one experiencing this condition while the rest of the world keeps on spinning. You have to be your own advocate and I had to find my voice when transitioning to adult care. My medical team take me seriously when I say 'something isn't right'.

3) **Find your people**
I missed four years in school from Year Six to Year Ten. I never experienced the stage of relying on friends rather than family. Only fairly recently I realised that this has impacted on my social interactions even to this current day. I struggled to be open and vulnerable with people outside of my immediate family. Why would I need to be when my entire world was my family when I was house–bound for four years? I don't like sympathy. But I get frustrated when

I do tell people about my health story and don't get the reaction and true understanding I feel it deserves. Therefore I continue to be selective with sharing my story. This is a work in progress.

4) **There is no set timeline in life**
As humans I think we have an innate fear of missing out or not being at the same life stage as others. I know I do. That old classic quote – comparison is the thief of joy – is pretty accurate! I have vast experience of being behind my peers in the 'norms' of life; when most of my contemporaries were going out to parties, I was home in my 'safe bubble', too ill to venture out. I missed my graduation, instead having to extend my degree due to my unreliable gastrointestinal tract and immune system! But I have learnt that this is OK. The only competition should be with yourself and the person you were yesterday. I've had life experiences, different to my peers, that are immeasurable in terms of what they have taught me. The feeling of life being paused, that the world is feeling at the moment due to Covid–19, is not new to us – the chronic illness gang!

5) **Our bodies are maps**
I heard a quote about 'our body being a map of our life' and I thought 'yes'! That really connected with me. I have scars on my hands from numerous cannulas, scars on my tummy from all the resections, I am the proud owner of a 'barbie butt' and I have my friend Neville (stoma) always with me wherever I go. My body is not 'typical' or the social norm of 'beautiful' that the media portray. But it sure isn't boring. It has lumps, bumps, moles and holes – that show the battles I have won during my 28 years on this planet. My stoma operation, age 19, was planned so I had time to mentally prepare myself. However it still took time and I am continuing to learn to live with Neville. I do not regret having him as he gave me the chance at 'living life' rather than 'barely surviving'.

6) **We are bloody resilient!**
I wouldn't change having Crohn's or my stoma. That might sound bizarre to some. I don't know who I would be without IBD. It's given me an abundance of empathy, shaped my career path and shown me how unbelievably resilient any IBD/chronic illness superstar has to be!

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.

Climb every mountain

Sammii

Paul Anderson

There must have been something in the water these last few months as we've had a number of people taking on some great hiking challenges to support us.

In August, exactly two years after she had stoma surgery, Sammii Reader supported by Mark and Catherine climbed Mount Snowdon and together they have raised well over **£1,200** for **Colostomy UK.**

In Sammii's own words: "I had always been determined that I would get fit and lose weight after having my proctocolectomy. But when, on the day immediately after my surgery, my older brother suggested we tackle Mount Snowdon when I was fully recovered, I was dubious to say the least!

Fast forward two years on, exactly two years from the very date of my surgery, I was stood at the very top of said mountain having an emotional hug with my brother"

They were followed in September by ex–rugby league star Paul Anderson and his wife Lisa taking on the challenge of the Yorkshire Three Peaks. Paul and Lisa have already raised over **£1,400** and, at the same time, created considerable awareness of stomas in general as well as of **Colostomy UK** and the work we do.

Birthday Bonanzas!

Thank you to everyone who has set up a Birthday Fundraising page on Facebook. It's a really easy and straightforward way to raise funds for **Colostomy UK.** For more details visit: **www.facebook.com/fund/colostomyuk**

Great ideas

Liam

Kerry Stafford

It's always great for us to be able to feature some of the wide variety of ways people fundraise for us. Back in August Liam asked his friends to help him get fit by choosing a different exercise for him to try, but on the condition they made a donation to **Colostomy UK** as well!

Kerry Stafford raised an amazing **£510** through her stall at her local village walking market. It was great to hear from Kerry how much she enjoyed fundraising for us and the positive impact it has had on her mental health. She also told us that as a mother of a child with a stoma it has inspired her to volunteer as well!

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 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**

Using Amazon on your smart phone

Turn on AmazonSmile in the Amazon app to generate donations.

Do you shop on Amazon? 0.5% of every order you place will go to **Colostomy UK** if you nominate us as your chosen charity. Just log in to your account or create one at **https://smile.amazon.co.uk** and search for Colostomy Association. Just remember to always log in through **https://smile.amazon.co.uk** and we'll benefit every time you shop. It's as easy as that.

In the bag!

If you're planning a wardrobe clearout did you know that 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?

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

For all other areas give them a call and they will be able to advise when they will be collecting near 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 than 1cm of envelope left around each stamp.
- Do not trim stamps too close so that perforations are damaged.

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

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

Raffle update

Thank you to everyone who purchased a ticket for our Annual Prize draw.

The winning tickets were drawn on 19 October. Congratulations to all our winners:

1st prize £2,500
Sid, Kidderminster

2nd prize £1,000
Ronald, Isle of Skye

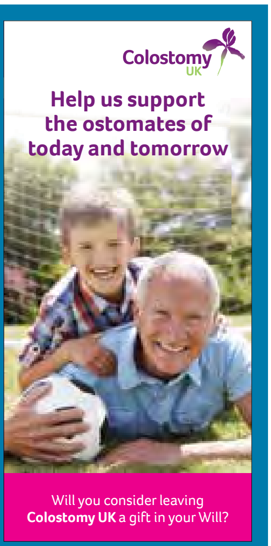
3rd prize £100 Catherine, Wellacre; Anne, Kent; Debra, Neath; Elizabeth, Wallsend; Patricia, Croydon; Wendy, London; Anonymous; Anonymous; Anonymous; Anonymous.

Trusts and Foundations

Thank you to the following trusts and foundations who are supporting our work in 2020:

The National Lottery Community Fund, Frank Litchfield Charitable Trust, Ernest Hecht Charitable Foundation, Ganzoni Charitable Trust.

Legacy



Colostomy UK

Help us support the ostomates of today and tomorrow

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

Giving in your will is a truly special way to make a lasting difference. It will help the ostomates of tomorrow, their family members and carers, receive life–changing support from **Colostomy UK.**

What your gift means

Legacies large and small can have an extraordinary impact on all the people we help and support. They can:

- Ensure there is always a voice at the other end of the phone.
- Train volunteers to provide support at open days and in hospitals.
- Help support our 'Stoma Friendly Society' campaign, our 'Fight the Poo Taboo' campaign and our projects including 'Active Ostomates'.

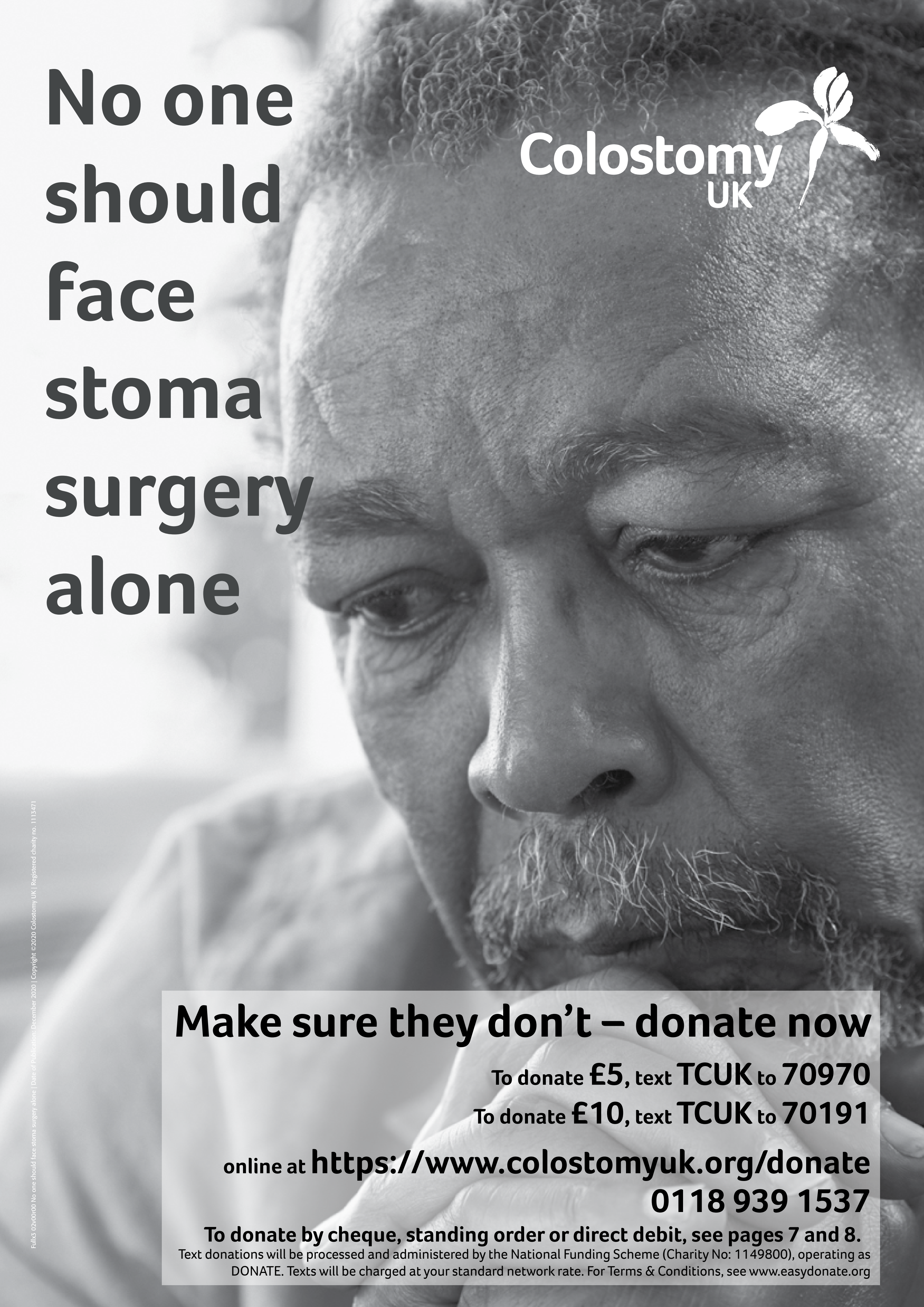
How to leave a legacy

A solicitor can help you to write a will or, if you already have a will, a codicil. Your legacy could be used wherever it is most needed or you can choose to support a specific area.

Your solicitor will need the following information on our charity:

Name:	**Colostomy UK**
Registered address:	**Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA**
Charity Commission registration number:	**1113471**

After you have provided for your loved ones we hope you will consider a gift to **Colostomy UK.**



No one should face stoma surgery alone

Colostomy UK

Make sure they don't – donate now

To donate £5, text TCUK to 70970

To donate £10, text TCUK to 70191

online at https://www.colostomyuk.org/donate

0118 939 1537

To donate by cheque, standing order or direct debit, see pages 7 and 8.

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

Your letters and e–mails

Ed's note: In the autumn we published a letter which raised the issue of naming stomas. This obviously struck a chord with people, judging by how many readers have written to me about it. I have included a selection below along with other mail received. It seems that for many people, having a name for their stoma, makes it easier to talk about. I was also interested to learn from Jo McKenzie, who is the longest–serving member of the Colostomy UK team with over two decade's experience, that stoma naming was once actively encouraged in some hospital stoma care departments. I hope you enjoy this edition's mailbag and please, keep those letters and e–mails coming!

Dear Sir

I have just read through my copy of *Tidings* and found it fascinating as usual. I have had a colostomy for about a decade now having had an Abdominal–Perineal operation plus Chemo and X–Ray to remove a tumour from my lower bowel and surrounding parts of my lower abdominal cavity.

Giving names to one's Colostomy is amusing. Sadly, all I have managed is to refer to it by the initials FFA, where the first two letters apply to its position and the third letter refers to its description that part includes something that I spell in English rather than the American word for donkey.

An oddity that does interest me is that since the operation I have become sensitised in some way to cocoa and chocolate. Almost certainly to the main drug in them that is Theobromine. I do not understand how the removal of about 9 inches to a foot of the end of my bowel has had such an effect. Even a tiny trace amount causes me to explosively "dump". I wonder whether others have similar strange effects from their diet. Oddly the initial pharmacology lecture, when I read medicine about half a century ago, was comparing the effects of Theobromine from chocolate and caffeine from coffee.

I can say however that my mind is still boggling at the idea of preparing for an 82–day cruise or holiday away. I would need a lorry to carry my bags and necessary bits and pieces. **Dr H C**

Dear Editor

I have just read the letter in the latest edition of *Tidings* about naming of stomas.

I had my operation for colon cancer in April 1999, and decided to call my stoma Tomas, an easy to remember anagram. **Lorna B**

Dear Editor

When I got my stoma 19 years ago, in North Tees Hospital Stockton–on–Tees it was normal to name your stoma. This was so the nurses and doctors could say: "How is ______ today?".

I named mine Poppy. But after leaving hospital and during a home visit, I asked my nurse if I could change it. She asked me why and I replied I wanted to change it to my ex–husband's nickname. She asked why and I told her and she laughed. She told her students at lectures and many others and I did also.

Unfortunately, I cannot repeat it in your magazine as it is a little rude! But to this day everybody laughs about it!!

Stay well, stay safe. **P B**

Dear Colostomy UK

Am reading the autumn 2020 issue and it is interesting how many of our friends have names now. Mine is Winnie (Yes as in Winnie The…) so imagine the surprise and pleasure in finding a lovely pic of Winnie and Piglet on page 27. Great magazine always look forward to receiving my copy. **D H**

Dear Editor

Referring to the letter in the autumn issue, I loved his stoma name of donut. It ranks with my favourite stoma names printed over the years in *Tidings,* the others being Etna (as in Mount Etna) and Winnie (the Pooh!). My own stoma is called Bilbo (Baggins) who entered my life 14 years ago after bowel cancer. I think giving it a name makes life so much easier as being so attached to you, it becomes very much part of the family! If Bilbo happens to make a rude noise, I can verbally excuse him and friends just laugh. If I say: "Bilbo was busy in the night", they all understand what I mean. Bilbo and I have a good relationship now after an initial learning curve and a few mishaps along the way! I quickly learnt what he doesn't like to eat eg: curry; chilli; garlic and broccoli are a definite no–no! I suffer the consequences if I ignore him but give him a "magic pill" to settle him down again. I have learnt to take his advice. We are very attached and will be friends for life! After all, he actually helped save my life, so the few restrictions he places on me are tolerated and accepted. **Sheila and Bilbo**

PS The "magic pills" are two 2mg Loperamide Hydrochloride capsules.

CONTINUED ON PAGE 43, COLUMN 1

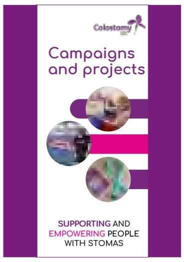
Colostomy UK literature range

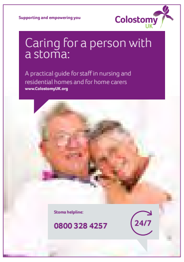
Have you seen our extensive range of support literature? Suitable for ostomates, family members, friends, carers and healthcare professionals.

To order your complimentary copies contact us by:

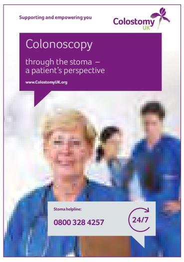
adminline:	eMail:	website:
0118 939 1537	info@ColostomyUK.org	ColostomyUK.org/information


Active Ostomates Sport and Fitness after stoma surgery


Campaigns & Projects Flyer


Caring for a person with a stoma

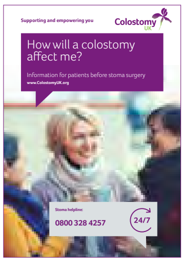

Caring for a person with a stoma and dementia

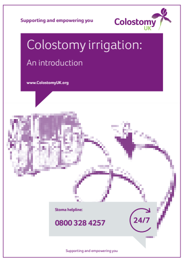

Colonoscopy through the stoma

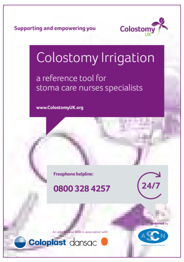

Fundraising Pack

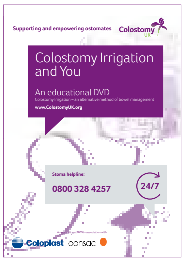

Healthy Eating

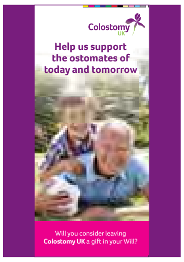

Helpline Cards


How will a stoma affect me?

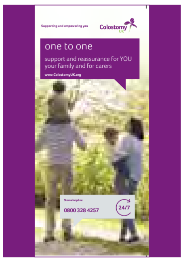

Irrigation Booklet


Irrigation DVD (nurses)


Irrigation DVD (patients)

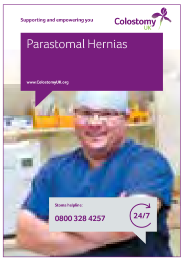

Legacy Flyer


Living with a stoma

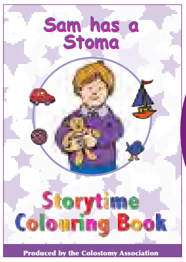

One to One (join us) Flyer


Ovarian Cancer and stomas

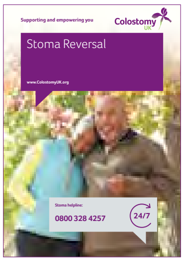

Pain & Discomfort

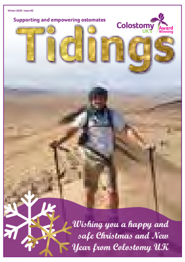

Parastomal Hernias

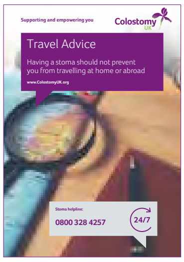

Rectal Discharge


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

CONTINUED FROM PAGE 41, COLUMN 2

Dear Tidings Irrigation

I have had my stoma for nearly four years now and for the first 18 months I used bags but then I read an article in *Tidings* about irrigation and after speaking to my stoma nurse she told me to watch the [Colostomy UK] DVD and then let her know my thoughts, which I did and these were positive. So she arranged to train me at home. It did not take long. After a couple of months I got the hang of it not without a few hiccups though.

About six months ago I read in *Tidings* of a person who was irrigating with a pump. After investigation I spoke to my GP to see if I could get one on prescription. He had not heard of it so suggested I spoke to my stoma nurse who loaned me the B.Braun Iry Pump and also to my GP (after I had been using it for a month) suggesting it would be beneficial to me. A few weeks later my pump arrived, unannounced but very welcome. I am very grateful to my stoma nurse and my GP and count myself blessed as my stoma nurse told me that one of her other clients had been turned down. I would recommend irrigating with a pump if this is possible. It has changed for the better what was a necessary chore. Many thanks for the *Tidings* magazine without which I would not be where I am today.

Robin S

Dear Editorial team

I have been a subscriber to **Colostomy UK** for about ten years now and have been taking advice and comfort from the *Tidings* magazine.

I have at last found the courage and hopefully a subject that may help fellow ostomates.

I am 69 years old and have had a stoma for eleven years now following my original diagnosis of rectal cancer. I also have a large parastomal hernia and for background I irrigate and have done so for about ten years.

I am always on the lookout for things to make my life easier and more comfortable and I have recently discovered a buckle free trouser belt (pictured below) that has transformed my comfort and confidence. It is a buckle free elasticated stretch belt which doesn't put any pressure on my stoma and allows me to undo my trousers and fasten them without having to undo my belt. I simply unbutton and then re–button with ease. I have dumped my braces and found this belt to be a revelation.

I have attached images from the Amazon page. The brand I have bought are Jasgood and there are other brands available suitable for ladies and gents; search for 'no buckle belt'. The belt length is adjustable and as you can see the belt has two press–stud loops that fix to the trouser belt loop.

I hope this tip helps.

Thank you all for everything you do for us all and please keep up all of your good work.

Mr T Y, West Midlands

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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Please allow 30 days for delivery.

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

☐ Please debit my Visa/Mastercard/Meastro 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

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

T60

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

Lynne and Phil’s story: “we are strong, we are a team, we are stoma twins”

Lynne Hancock and Phil Maddocks

The one thing we have realised is that in our four–year relationship, two of those years have been marred by our sudden and unexpected illnesses. Little did we know on our first date that we’d both end up with stomas!

Lynne’s Story

My stoma journey began one day in July 2018. I went from eating my breakfast and having a slight ache in my groin, to full on ‘ten out of ten on the pain scale’ agony in less than an hour. Initially I tried to take a bath to ease whatever it was but quickly had to shout out to my son Aidan for help, whilst pulling the plug out with my toes. The paramedics found me naked with poor Aidan trying desperately to cover my shame!

Appendicitis was diagnosed and I was scheduled for surgery within 24 hours. I wasn’t nervous, I would have endured anything to end the pain.

Phil: *I received a call from Lynne’s son out of the blue one sunny summer day to tell me that Lynne had been taken into hospital and was in great pain. When I got to the hospital, she was being given pain relief but was clearly in a lot of pain and discomfort. Initial suggestions of appendicitis were mentioned, but I had a feeling that it wasn’t going to be straightforward.*

The surgery took around three hours and when I awoke I was surrounded by a team of people, including the consultant who explained that my large intestine had ruptured, possibly due to diverticulitis and a stoma had been ‘fashioned’. My face must have looked particularly blank, I had no idea what a stoma was! He finally told me that I’d had a colostomy, I’d certainly heard of one of those!

Phil: *Following Lynne’s operation, she casually told me that she now had a colostomy. I remember at that point not wanting to let her see how shocked I was...it was an exercise in being calm and collected for me and just being there for her. I had lots of questions...I had lots: how will she cope? How will I cope? How long will this stoma last? However, the stoma paled into insignificance because I was so relieved to see my loved one had survived the operation.*

Two weeks into my painful recovery, it still hadn’t sunk in that the word colostomy and my name should ever be part of the same sentence. During this time, the lining of the stoma became necrotic and when a consultant attempted to view the length of dead tissue with a camera, my temperature spiked and I was sent straight back to theatre for surgery that lasted six hours. We don’t know exactly what happened, but something went wrong, and I ended up in Critical Care. Phil was called in the early hours and told to get to the hospital straight away.

Phil: *We then entered a very difficult period whereby Lynne’s recovery was being marred by complications with necrotic tissue. Fast forward a little and I remember leaving the hospital feeling very distressed as Lynne waited for her second operation which was to take place at some point during the night.*

I was expecting a call from the hospital to tell me that Lynne had had the operation. That call never came. In the early hours of the next morning, I phoned Lynne’s ward and was advised to come in as soon as possible as Lynne had been sent to intensive care. I dropped my children off at 6:00am at my ex mother–in–law’s, rushed to the hospital and found Lynne in a great deal of discomfort. Over the next few weeks’ Over the next few weeks, I visited Lynne every day and was as supportive as possible. Prayers were said, candles were lit in churches and all I did was hope.

Three weeks later, I was allowed home with this new and alien way to poop, and absolutely no idea how life could ever be close to normal again. Phil had been an absolute brick throughout the whole process, but I felt I had no dignity left. I couldn’t accept that he had to see me with a belly full of stitches and that horrible bag. In those dark days, I genuinely thought any kind of sex life was a goner! Phil, however, never faulted in trying to make me feel wanted and desirable, despite the bag.

Phil: *I endeavoured to reassure her that everything would be okay, we are strong, we are a team. We managed to find a ‘new normal’ as Lynne took*

the first steps to recovery.

It was difficult for me to overcome what had happened and I can honestly admit to there being lots of tears in the bedroom. My confidence was squashed and I was left with such a negative body image, I just couldn't see my way out if it.

Phil's story

In 2003, I was diagnosed with Antiphospholipid syndrome (APS).

The NHS website advises that Antiphospholipid syndrome (APS), sometimes known as Hughes syndrome, is a disorder of the immune system that causes an increased risk of blood clots. People with APS are at greater risk of developing conditions such as deep vein thrombosis, arterial thrombosis, and blood clots on the brain.

I was in my mid–30s at the time and it was discovered when I developed an intestinal clot. I was subsequently put on Warfarin to keep my blood thin. Despite this, shortly after Lynne became unwell, a new clot started to form. Hence, the new 'normal' we had become accustomed to after Lynne's stoma surgery came to a crashing end a year later. The very same hospital door opened once again, this time to admit me for life–saving surgery. After the operation, I heard that I'd now got a stoma too (snap!). Well, I didn't want to be left out, did I!

Lynne: *In the meantime, Phil's health was gradually deteriorating and through the months and despite many tests, he suffered from grumbling pains and other symptoms and his weight dropped to seven stone. In September 2019, he finally had life-saving surgery to remove the majority of his small intestine which lead to his ileostomy. He spent five days in a coma in Critical Care (the same pod that I'd been in the year before). When he awoke, he found out about his stoma when a nurse casually mentioned it in a conversation, she had no idea he had yet to be told.*

In summary, I landed in a recovery ward amidst a haze of missing information as I attempted to find the skills necessary to maintain a high output stoma (and at that point it was very high). I know I wouldn't have coped had it not been for Lynne's experience and knowledge. I was lucky that she had undergone a year of colostomy management – she may not see it as luck, but I am forever thankful to her. Everybody deals with a stoma bag in a different way. With the help of the excellent stoma nurses, I found a way of securing my bag so as not to wake up in a pool of 'output' all the time (which happened a lot!). Some aspects of my recovery are hazy, but my understanding of how Lynne must have felt in those early days is absolute.

Lynne: *From my perspective, I can honestly say this was the worst time of my entire life. The surgeons told me that the survival percentage for him was very small, he had next to no strength left to survive and suggested that if I had some last words to say, to say them there and then. Only those who have experienced this can understand that feeling, there really are no words for it. You make deals with God, the universe and anything that will listen, anything just so your loved one will survive. Thankfully he did, but spent roughly five months in hospitals in Stoke, Manchester and Salford. His road to recovery was arduous, and still is, particularly as his stoma is so problematic. He has many leaks and struggles with his stoma, a lot more than I do with mine. His journey is still ongoing and with his TPN nutrition and constant monitoring, his health has become a full-time job.*

Intimacy is a huge challenge and I'm lucky to be with a person who really and truly understands this. We tackle our stoma twin status with love, understanding and humour. At this point neither of us know whether reversals are possible, so we look after each other as best we can and, let's face it, we are never short of stoma kit! 🟩

Colostomy UK: active ostomates®

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

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.

Sometimes it just takes the right words…

When you have a stoma sometimes the idea of taking part in activities for the first time can be daunting. Sometimes the mental hurdles are bigger than the physical ones. As Ian's story shows sometimes it just takes the right words to empower someone to take that first step…

"Earlier this month, my son's football club held a dads vs veterans game which I volunteered to play In. In the week before the match, it was revealed that due to the coronavirus the changing rooms would be closed and the kits would be given out on the day, which meant we would have to get changed on the touchline, in a public park.

When I go swimming, I can't hide the fact that I have had stoma surgery, but I'm not what you would call an 'out' ostomate, eg a person with a stoma who advertises the fact. For me getting changed on the touchline was a concern. My son is now 12 and, like his schoolmates, is navigating the changes to body and mind that adolescence brings. Some of the dads playing were parents of my son's schoolfriends. I have not been open about my stoma with these people because I worry that if one parent knows, and then their son knows, who tells another person, and they another, or it gets shared on a WhatsApp group etc, then it could prove more than problematic for my son. I think you can guess where I'm coming from!

Not everyone is open minded enough to accept something that is different. In common with other ostomates, I have had to endure my fair share of verbal abuse and discrimination, most of which stems from general ignorance about my needs. Naturally, this made me apprehensive about the touchline change. In fact, I was downright worried about being 'outed'. So much so that doubts about taking part started to creep in and began niggling away at my already fragile confidence. I spoke to my son, who despite his age understands the issues an ostomate can have. Most recently he, along with ***Colostomy UK,*** *were able to support me when I was badly treated at a holiday park. Bullying is a despicable act and to be on the receiving end of it is terrible. Being prepared to do anything to prevent and avoid this, I started to think about pulling out of the game. But I realised this would probably just create a fresh set of problems, as people would start to question why. Some of the parents and children knew about my journey with Crohn's, but not my stoma.*

As I mentioned earlier, ***Colostomy UK*** *have supported me in the past, so I dropped them a message on Twitter to see if they had any suggestions. I'm glad I did! They put in contact with an ostomate who plays team sports regularly. He was able to reassure me that playing would be fine, and with a clear mind suggested a solution so simple it makes me look foolish writing it down: simply keep my t–shirt on when getting changed. And it was that simple, albeit a little warm when I was playing and got up a full head of steam! I didn't set the world on fire. Miskicks seem to have become a part of my playing style now, although I did make two goal line clearances. I also made some "telling passes" to our star striker (his words not mine). I managed to play for 70 minutes having come on as a substitute. Despite the heroics of our scratch side we went down fighting, losing 4–3, which for a team with an old codger like me in it was a huge achievement.*

I feel proud to have taken part. The day after the arthritis wasn't too happy though, nor were my muscles, but I think I'll survive!"

#ActiveOstomates

New merchandise!

Whether you're an active ostomate or just like to look the coolest cat on the block we have a range of Team Colostomy UK clothing to suit everyone's tastes. The latest additions to our range include our new pink–hooded sweatshirt and cycling shirt. To see the full range just visit our online shop at **https://colostomyuk.bigcartel.com/**

All profits from sales of our clothing range support more people with a stoma to get active through our Active Ostomates project.

Active Ostomates: At Home

Our Active Ostomates: 'at home classes' have been running since April, and we've been delighted by the numbers of people joining us online for regular art, chair yoga, and mindfulness and meditation sessions.

We've got some great new activities planned for 2021 and some old favourites are returning as well.

To keep up–to–date with all the latest news and activities, visit the Active Ostomates section of our website **https://www.colostomyuk.org/active-ostomates/**

Top tips!

We recognise taking that first step back to playing sport or exercising after stoma surgery can be difficult for many ostomates. Hence we've produced a series of 'top tips' featuring experience–based guidance from ostomates who are successfully taking part in their favourite activities again. At present the series includes tips on playing football, rugby league and golf, along with running and swimming when you have a stoma. Further titles will be added.

You can read the series online here **https://www.colostomyuk.org/category/top-tips-for-being-active/** or call us on **0118 939 1537** and we'll send you some copies in the post.

Sport and Fitness After Stoma Surgery

Colostomy UK's very own *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. They 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!

Supporting and empowering you

Colostomy UK

Active Ostomates®

Sport and fitness after stoma surgery

www.ColostomyUK.org

#ActiveOstomates

Freephone helpline:

0800 328 4257

24/7

The booklet also signposts to team and individual sports and activities that you can take part in within your local community.

You can download your free copy online at: **www.ColostomyUK.org/active-ostomates/**

You can also call us on **0118 939 1537** or email: **info@ColostomyUK.org** for a copy.

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.

Halfx3 01v00r00 FB Birthday fundraiser | Date of Publication: September 2020 | Copyright ©2020 Colostomy UK | Registered charity no. 1113471

New products

and services

Tidings is always **interested to learn about new stoma care products and services** from **manufacturers and suppliers.** If you have found **a stoma care product** or **service beneficial to 'living with a colostomy' please let *Tidings*** know. **YOUR findings could make ALL the difference to others.**

CUI WEAR

NEW

New Improved anti–roll hernia support belt

CUI WEAR – Introducing the New Improved anti–roll hernia support belt with patented glove design for ease of application.

The new enhanced anti–roll elastic edging minimises rolling and movement of the belt along with the new velcro fastening on the glove to improve shape retention. A luxurious feel with enhanced performance so you can wear with confidence.

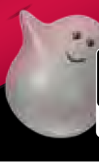
Call **0800 279 2050** today

See our main advert on page 56.

Say hello to Genii

The worlds first stoma bag with patented Sil2™ Technology.

The silicone flange is breathable to moisture, sticks firmly but won't go gooey, mushy, or sting when you remove. Soft, water-resistant fabric feels light, comfortable, barely there. Choose from three shades and wave goodbye to sore skin.



See our main advert on page 16.

Join Colostomy UK today!

As a registered supporter of **Colostomy UK** you will receive a welcome pack full of useful information. Each quarter you will also receive a copy of this award winning magazine called *Tidings*, and much more…

- Access to the latest stoma product updates.
- The latest news and views from **Colostomy UK** direct to your inbox.
- The option to take part in surveys and have your say on the future of stoma care in the UK.
- Help us be the voice of ostomates.
- Access to our support literature and factsheets about all aspects of living with a stoma.

Joining is free and friends and family are welcome to join too.

www.ColostomyUK.org/join-us/

GET 20% OFF

Breathable Shorts & Briefs

Unisex design

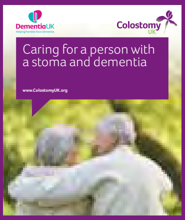
- Supports abdominal muscles, helps to prevent and support a hernia
- Designed to be worn over a stoma pouch without restricting the natural output from the stoma
- Variety of sizes available in both shorts and briefs

New and innovative range of medium support briefs and shorts available to purchase direct from Suportx. High waisted with breathable technology.

See our main advert on page 20.

Colostomy UK

The more you DO nate the more we can DO



24/7
Stoma Helpline
0800 328 4257

Ways to donate

Online at:

https://www.colostomyuk.org/donate/
www.justgiving.com/colostomyassociation/donate

Text giving:

To donate £5, 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

Fullx3 01v01r00 The more you DOnate | Date of Publication: December 2020 | Copyright ©2020 Colostomy UK | Registered charity no. 1113471

News from support groups across the UK

Support groups are places where people can share personal stories, express emotions, and be heard in an atmosphere of acceptance, understanding, and encouragement. Participants share information and resources. By helping others, people in a support group strengthen and empower themselves. At the moment, support groups are unable to meet face–to–face, but if you are interested in joining or finding out more about a local group, then we encourage you to make contact with the organisers. You will then be all ready to attend once lockdown restrictions are eased. We also know some support groups are meeting via Zoom.

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

King's Lynn & District Ostomy Support Group

Meets at the Reffley Community Hall in King's Lynn on the first Saturday of March, June, September and December.

The group covers north and west Norfolk, Cambridgeshire and Lincolnshire and is run by colostomy, ileostomy and urostomy patients, for patients, their families and friends. Informative talks on health–related matters of interest to the group are given by both healthcare professionals and guest speakers. Refreshments and a raffle are provided.

The group provides a peer–to–peer forum for patients to meet up with others and share their support and tips in a friendly, informal environment to encourage wellbeing and regain self–confidence.

We are disappointed that we have been unable to arrange meetings since the Covid–19 lockdown in March 2020 and know that many of our members share our disappointment, especially as the Christmas 2020 meeting has now been cancelled.

We would nevertheless like to reassure them that the meetings will recommence just as soon as Government safety guidance allows and hope to have further news regarding the March 2021 meeting early next year. We look forward to seeing our friends and group members, both old and new, just as soon as we can – please watch this space for any news!

In the meantime, please telephone a member of the Committee for any further information:

Elspeth Hardy	**01553 775 698**
Mary and Chris Thompson	**01406 363 756**
Mo Ford	**01263 712 143**
Christine Spicer	**01553 674 962**

Chris Thompson
On Behalf of the Committee:
King's Lynn & District Ostomy Support Group

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

Jersey

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

England

Berkshire

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

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

Bristol

Bristol Ostomy Self Support (BOSS)
Janet T: 01934 248 114 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

Crewe & District South Cheshire Stoma Group
Mrs Joan Owen T: 01270 764 075
E: joan.o@btinternet.com

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: 07923 975 051 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 Quigle 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: https://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

Second Chance Ostomy Yorkshire
Jackie Butterworth,
E: Secondchanceostomyyorkshire@gmail.com T: 07544 882 353

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

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 (DD)

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
Jim Krasewitz T: 07729 771 350 or
Susan Latimer T: 07790 929 268

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)

Gwent

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

Mid Glamorgan

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

Pembrokeshire

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

Powys

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

Rhondda Cynon Taf

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

Swansea

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

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