Winter 2021 | Issue 64

Colostomy UK

AWARD-WINNING

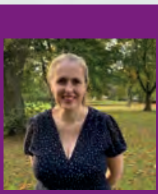
Tidings

Supporting & empowering ostomates

Make sure you're heard...

complete our **Stoma Aware Survey** on page 19.

EMMA HOWELL
Goodluck
and goodbye



ZOE TURNER
An unforgettable
Christmas

Real stories
Real people

Advertorial

CONFIDENCE BE®
MY PROFESSIONAL PERSPECTIVE

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

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

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

WHAT FACTORS DO YOUR PATIENTS LOOK FOR IN PRODUCT CHOICE?

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

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

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

WHAT ARE YOUR PATIENTS FIRST IMPRESSIONS OF CONFIDENCE BE®?

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

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

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

After wearing Confidence BE® you could see the difference – the product change gave him a lift… it really gave his recovery a boost.

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

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

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

salts HEALTHCARE

British Skin Foundation – Recognising Salts research into healthy stoma skin

Skin Health Alliance – DERMATOLOGICALLY ACCREDITED

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

CONFIDENCE BE®
For all you want to be

Colostomy UK

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Dear readers

If all goes to plan, you will be reading this edition of Tidings a week or so earlier than in previous years.

This was a deliberate decision on our part as, with Christmas effectively cancelled last year, we figured that people might be feeling festive just a tiny bit sooner than normal… I certainly hope I am (it's mid-September as I write this). It would make a pleasant change from my usual 'last minute.com' approach. I'm one of those flustered people you see rushing around the shops on Christmas Eve with panicked looks on their faces!

We have a great range of Real Lives stories for you to enjoy. We hear from Zoe Turner about what it was like to spend Christmas in hospital following emergency stoma surgery. Helen Marshall explains how she has spent her last two Christmases as an ostomate and imparts some good tips on eating over the festive period. If you are one of the many who struggles in the face of Christmas treats and goodies, then you will hopefully find Sophie Medlin's article on pages 44-46 useful. In this issue we also have an article about hydration from Pooja Dhir. Pooja is a specialist dietician who works with Sophie.

Shifting the focus away from Christmas, Susan Jeffrey courageously recounts her experience of having emergency stoma surgery and then losing her partner to cancer just two weeks later. Many ostomates will be familiar with Christine Wright's experiences in those early post-operative days. Like Susan's story, Christine's highlights how much we come to rely and depend on our family, not just for emotional support but also for practical things, like confiscating heavy objects and telling us to take things one step at a time! Our last story is from Carol Peters. With people starting to think about foreign holidays again, there is plenty of good advice for would-be jetsetters.

Cath Dixon, who is a clinical nurse advisor with Fittleworth Medical Ltd, has written this edition's Dear Nurse, contributing a short, but nevertheless important piece on stomas and medication. To round things off, we have all the regular Colostomy UK features, allowing you to catch up on the charity's news, campaigns, projects and volunteers. This includes a brief message from Ian Daniels our President who, as many of you will know, is a consultant colorectal surgeon. Finally, I invite you to do our Stoma Aware Survey, either by filling in and returning the form on page 19 or completing it online. The responses we receive will help guide our future plans.

Happy Christmas!

Richard

Richard Biddle
Editor, Writer & Researcher

Colostomy UK

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

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

How to contact us

Stoma helpline for:

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

Adminline for:

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

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

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

Social media:

Find us on **Facebook**

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

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Donating to Colostomy UK

An annual donation of £25 (or what you can afford) allows us to produce Tidings and to continue our vital work, supporting, and empowering ostomates – see page 29 for our donation form.

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

Colostomy UK news

Libby Herbert
General Manager
Libby.Herbert@ColostomyUK.org

Naidex

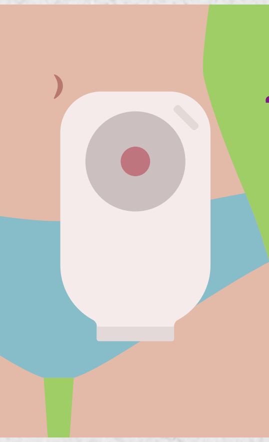
Back in September, Libby Herbert, Colostomy UK's General Manager and Giovanni Cinque, our Fundraising and Development Manager attended Naidex, in Birmingham.

Naidex is now a well-established event for supporting independent living, where exhibitors showcase solutions to improve mobility and accessibility. It proved an excellent opportunity to promote Colostomy UK, our services and our campaigning and advocacy work. Our president, Ian Daniels FRCS, was also a keynote speaker at the event, which of course helped our profile no end and led to lots of people visiting our stand afterwards!

Association of Stoma Care Nurses (ASCN) Annual Conference

ASCN has been running an annual conference for many years now and provides a great opportunity for the stoma care industry, healthcare professionals, patient advocates and stoma charities to meet, learn from one another and hear about the latest research.

Sadly, last year's event had to be cancelled because of COVID-19, but the conference returned this October, albeit in a 'virtual' form. You can see Colostomy UK's 'virtual' exhibition stand in the picture (below). All that's missing is an avatar of Richard Biddle and one of Jo McKenzie, our Senior Support Coordinator, who represented us at the event and were ever ready to talk to visitors to our stand.



Telling the Human Story

We were delighted to be asked to attend a workshop hosted by the charity GutsUK, which explored the human side to living with ulcerative colitis (UC).

There were representatives from a number of charities present, along with three people with UC, all of whom had stomas. Richard, editor of Tidings, went along on our behalf. There were three sessions in all, which tracked the patient journey: 'The route to diagnosis'; 'Treatment'; 'Living with UC'. The hope is that this workshop will eventually lead to some practical changes being made to each stage that will benefit patients.

SOCIAL CARE ANNOUNCEMENT

The future of Health and Social Care has been in the news a lot recently. Colostomy UK along with seventy other charities are members of the Care and Support Alliance.

The Alliance campaigns to improve the provision for and funding of Social Care in the United Kingdom. In September the Government announced its decision to fund improvements in Social Care through an increase in National Insurance contributions.

However, there is a lot of 'devil in the detail' which we need to understand before reaching a final judgement.

If you have any questions around, for example, eligibility for social care, then please email us on **Info@ColostomyUK.org** and we will do our best to help or point you in the right direction.

We are recruiting

We currently have five vacancies: Volunteers and Community Manager; Public Relations and Engagement Manager; Finance & Operations Manager; Support and Finance Coordinator; Fundraising and Communications Executive. To find out more about the roles, what they entail and how to apply, please visit our website.

www.colostomyuk.org/were-recruiting/

Colostomy UK Campaigns: Stoma Aware Day

The first Saturday in October is traditionally World Ostomy Day. At Colostomy UK this is the second year that we have used the day to acknowledge our own Stoma Aware Day, which is part of our wider Stoma Aware campaign.

Our Stoma Aware campaign aims to tackle the stigma that exists in some areas of society. We believe that the more people know about stomas and the reasons for stoma surgery, the easier it will become for ostomates to lead fulfilling lives.

We see Stoma Aware Day as a marvellous opportunity for the ostomate community to come together and tell the world what a stoma is, and the challenges people with stomas face every day. We had a brilliant response to our campaign on social media with hundreds of people telling their stories and sharing our educational graphics. Indeed, you may have joined in yourself or perhaps seen some of this activity. If you did, then the image on the front cover of this Tidings will probably be familiar!

To find out more visit: **www.colostomyuk.org/campaigns/** Help to shape our Stoma Aware campaign by completing the survey on (page 19).

Colostomy UK

volunteers

Goodbye and Good Luck!

Emma Howell left us as our Volunteers' Manager in August after a number of years in the post. It was certainly an eventful few years too, with all the changes to volunteering wrought by the coronavirus pandemic. We are very grateful to Emma for all her hard work. Amongst other things she took forward the roll-out of our online volunteer training programme and started our 'virtual' coffee mornings as a way to ensure we could all stay in touch.

We are currently recruiting Emma's replacement: see Colostomy UK news (pages 6-7) and our website for further details.

Volunteers Return to the Colostomy UK Office

We were thrilled to be able to welcome back our office volunteers this summer. Jackie Dudley is one of them, who has been helping us with some of the behind-the-scenes activities that go on with our annual raffle. Although some of these tasks aren't particularly interesting (indeed some would say boring!) Jackie found it gave her the space for her mind to wander…

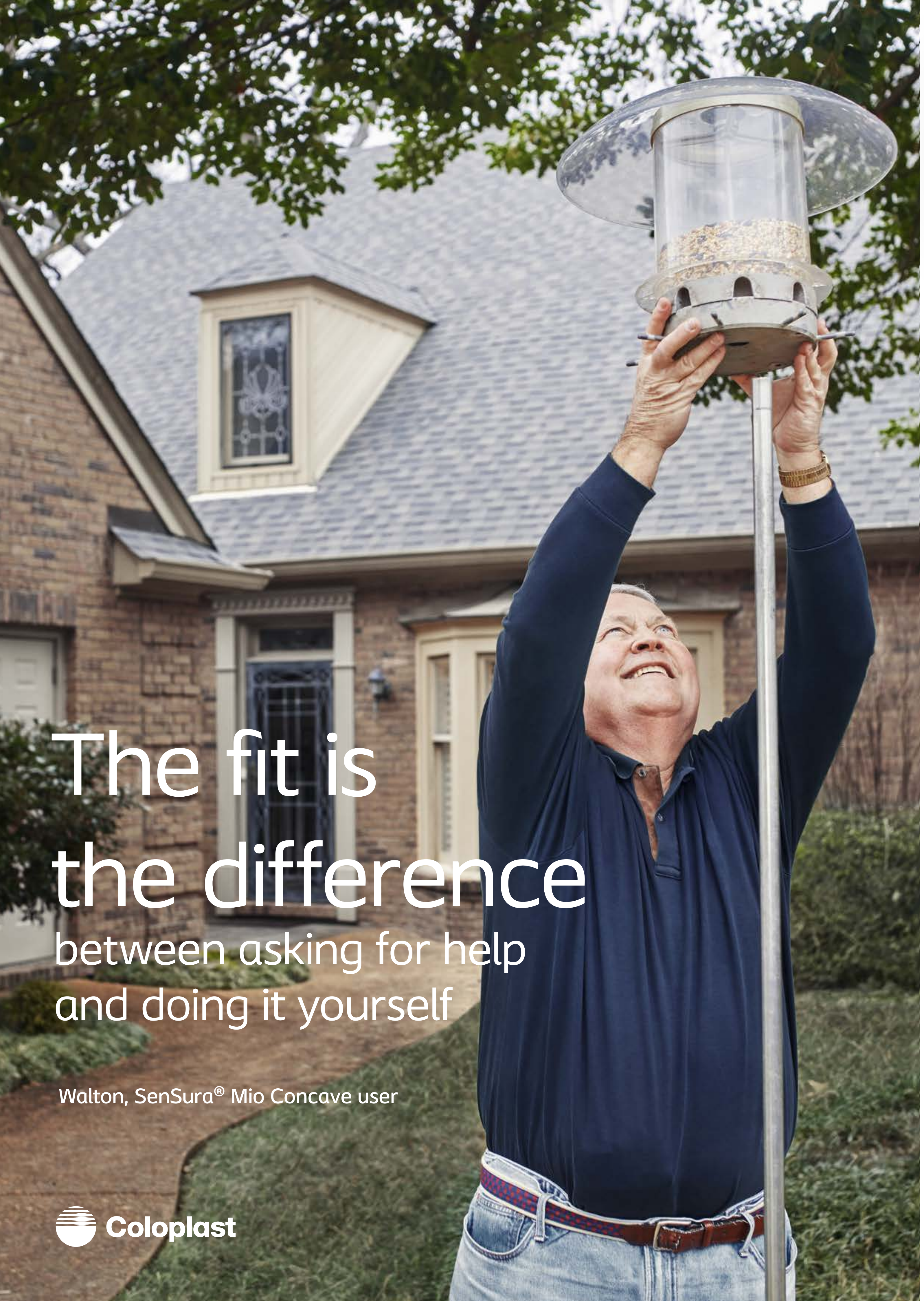
"I have been a Colostomy UK volunteer for many years and in the last months I have returned to the office on a Wednesday to resume my duties! These are mainly things that the office team don't always have time to do.

My job recently has been to fold up the many raffle tickets that readers have bought to support Colostomy UK. It is quite therapeutic to separate each ticket, ensuring that each stub has full details written on the ticket – before I fold them in half and put them in the very large container ready to be spinned and mixed well, before the draw.

During the separating and folding of the tickets, my mind has wandered. On occasion I have found myself thinking, as I read all the names on the tickets: what if I wanted to change my identity (I watch too many TV programmes) what name would I choose? Reading the addresses I also wonder where certain places are and vow to go home and get out a map of the British Isles! Many addresses are from places that I want to visit. So I've added another list to my 'to do list'!

BUT – what has made me very proud of all who have contributed so generously to the Colostomy UK raffle is the knowledge of how many other charities you are supporting. How do I know? Because many of you have been using printed address labels on your tickets rather than writing your address by hand. These labels have pictures of animals (Dogs Trust, Cats Protection, RSPCA, PDSA) 'Garden' charities have pictures of the loveliest flowers or plants, while cancer charities have their logos and the RNLI lifeboats. It has been an eyeopener for me to see that people are helping so many good causes.

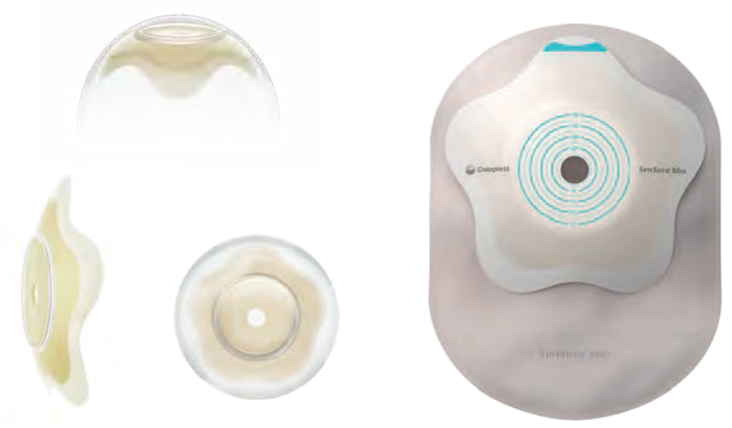
When Colostomy UK runs its raffle each year, it's never taken for granted that people will take part, but I can't begin to tell you how important it is. Every ticket you buy goes directly towards helping and supporting new and old ostomates. As I fold each ticket I wonder if it is the winner. Good luck to the winner - but I think that the spirit in which you support Colostomy UK is the biggest winner of all."



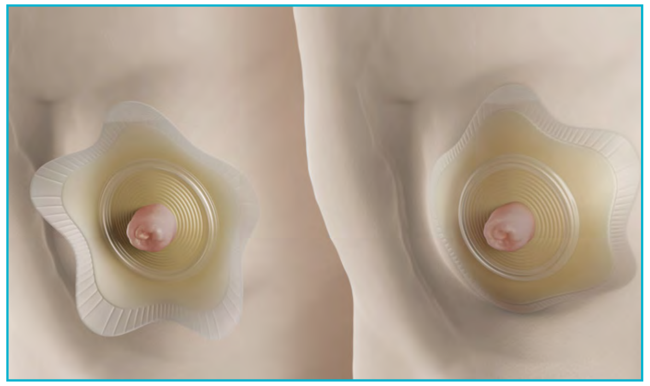
"My body changed, but my stoma bag didn't. That's why it didn't work as well anymore."

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

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



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



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

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

Request your FREE sample

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

First name ______________________

Surname ______________________

Date of birth ______________________

Email ______________________

Date of Stoma Surgery ______________________

Telephone No. ______________________

Signature

How your information will be used - By providing your personal and sensitive personal data on this form, you are consenting to Coloplast Charter using it for administration and analysis purposes and to process your order. We may share this information with healthcare professionals and other companies required for the delivery of your products or as required by law. We may also contact you to ask you to clarify your requirements and to ask you to complete customer satisfaction or other surveys, and may use 3rd parties to handle this as outlined in our Privacy Policy which can be found at Coloplast.co.uk/privacy. We often keep customers up to date with the latest information on the products and services we offer. Please indicate if you would like to be kept informed by:

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Regulated by
CareQuality Commission

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

OC_AD_CUK_Autumn2021

A CHRISTMAS

I will never forget

ZOE TURNER

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

My name is Zoe Turner, I'm 47 and I live in Leeds with my partner and two children, Erin aged 14 and Jake aged 10. I work at ITV in Leeds as a crew coordinator for Emmerdale. When I'm not at work, I enjoy exercising, reading, and spending time with my kids. Prior to Christmas 2020, I was one of those people who didn't know what a stoma was. Little did I know that one day I would end up with a bag on my abdomen, into which waste would go. People will be amazed to learn that my life changed after eating a dodgy takeaway meal, but when I look back there had been some indications for many years that everything was not quite right with my body.

I've always had what I describe as a "dodgy tummy". I seemed to be more sensitive to foods than other people I knew when I was growing up. Deep down I knew that something was not normal about my reaction to certain foods. I was underweight and developed later than my friends. I now know that these are classic symptoms of Crohn's disease. Eight years ago I experienced severe abdominal pain, which was suspected to be a grumbling appendix. No investigative work was done by the hospital, and even when I paid for a private consultation, no one was willing to put a label on my mystery ailment.

On the 14 December 2020, I ate some fast food chicken that gave me food poisoning. Instead of recovering after a few days, I got worse and worse, and after a week of being in bed, not eating and everything giving me green coloured sickness and diarrhoea, I was finally sent to A&E by my GP and the 111 service on the 20 December. Once I was there, they took my temperature and it was high, so they had to situate me in the Red (Covid) Zone, which was scary in itself. After being in a cubicle for what felt like hours, with people checking on me at various intervals, I was finally moved to a private room in the infectious diseases ward, as they thought it was severe gastroenteritis. All this time I was on rehydration fluids but nothing was helping. A nurse came to take samples and couldn't tell where the sample was from (which end!) as it was so green and runny. At this point I started to realise that this could be quite serious.

The next day a consultant came to see me as she thought I had appendicitis and sent me for a CT scan and a chest X-Ray. I had to have an NG tube and a catheter in, which was not nice! A different consultant then came to tell me that I had a bowel obstruction and that they were meeting in the morning to discuss which route to go down: surgery or medication. The next day the gastroenterology consultant came to confirm that I almost certainly had Crohn's disease. It was also my daughter's 14th Birthday, so I had to Facetime her to see her opening her presents. Later that day I was told that in all likelihood I would be having surgery and they started prepping me for it, including drawing a circle for my stoma. To be honest, I was so out of it by this point I didn't care what they did. In the early hours of 23 December, the nurse came to see me and I was told that I was first on the list for surgery. She brought me a gown and I had just enough time to ring home and let everyone know what was going on before I was wheeled down to the theatre for my ileostomy!

Initially I didn't want to look at my stoma, thinking: "what the hell is this on my tummy". It all seemed so strange. As my surgery was not done laparoscopically, I had a big cut in my stomach. I shuffled around the ward like an old lady, and every time I needed to empty or change my bag, I had to ring the buzzer for the nurse to help me. I was worried about changing the bag on my own, but I was given time in the hospital to get used to changing it, and so before too long I found it easy. Now I just whack a bag off and whack a new one on!

Hospital during Christmas was not the best place, especially as there were no visitors allowed. They didn't really make a fuss at all on Christmas Day, which in some ways made it easier, as I just tried not to think about it as I knew it would upset me. I Facetimed my family through the day, especially at present time for my kids as I still wanted to see their faces when they opened their presents. The hospital volunteers provided everyone with a small present… I got a men's Lynx gift set , which to be honest came in really handy. I was admitted into hospital with nothing as I really didn't think I would be there that long! The staff were all really kind to me and understood how upsetting it was. There was also a lady in my ward who tested positive for Covid, so the hospital policy was to move her into isolation and then close the ward for deep cleaning as soon as everyone had been discharged.

By New Year, there was only me and one other lady on the ward, which didn't help the feeling of isolation. I just wrote off Christmas completely, and when I finally was discharged on New Year's Day, I went home and had a small celebration with my family, but mainly just the present opening as I was very wary about food at that point! Christmas 2020 is definitely one that I will remember forever - and not for the best reasons. I've never missed a big event with my family, or even been away from them for that long, so I really struggled with the emotional / mental effects much more than the physical effects of the operation. But I had to remind myself that if I hadn't gone into the hospital when I did it could have been much more serious. I also have lots of appreciation for all the NHS staff that worked all through Christmas looking after everyone.

I'm hoping this Christmas will be completely different from last year. I plan to spend it with all my family. Our family spreads out across the country, so Christmas is usually the one time of the year that we manage to see each other. As my children get older I'm trying to appreciate every big occasion while I can still make it special for them!

When I was in hospital, there wasn't much I could do, so I started looking at social media for support for having an ileostomy. I found the Facebook Page "Colostomy UK Support group" and immediately found a great network of people who were so accepting about the condition, and really helped me not to feel so isolated.. I also follow Mr Colitis Crohns on Instagram. He's so positive about his stoma and makes it seem normal. I'd encourage anyone who's struggling to start following pages / people like this. I even got one of his support belts for when I started exercising again!

My consultant was very positive about the active life I was going to be able to have with my stoma, and he encouraged me to get back to normal. I attend Group PT Sessions (Overpower Leeds), and when I was ready and fit to go back to training, Grant, my trainer, was amazing at checking in on me and making sure I could manage in the sessions. Exercise, for me, is so important to both my mental and physical health, and I was really worried that my stoma would stop me doing it. I actually exercise more than I ever have done, because it makes me feel stronger – if you are stronger physically, then everything else becomes stronger too. I'm now back to working full strength, which is amazing. I am getting ready to go back to the office after a long time working from home due to the pandemic, but the media industry is pretty relaxed, so I am not anticipating any problems settling in.

I have always been open about my stoma, and I find that people are supportive and understanding. They are interested to know what happened, and how my stoma works. If you hide your stoma away then no one will be able to support you or check in on you, like my trainer Grant does. The reality is more positive than you think it will be, as most people are nice people. I do have down days, and days where things don't go to plan - bag leaks are always not far from my mind - but instead of dwelling on it and letting it get me down, I treat it as a small part of my new life, and can even laugh about it now! It doesn't define me or my life.

Christmas with a Stoma

HELEN MARSHALL

With the festive season now upon us, I thought new ostomates in particular might be interested to hear how I spent my first two Christmases after stoma surgery.

I learned some lessons along the way, which I hope readers will find useful.

My name is Helen. I am 51-years old and live in the beautiful countryside just outside Halifax in West Yorkshire, also known as Happy Valley for those familiar with the TV programme. I worked in policing for 25 years and enjoy walking our border collie dogs and supervising my husband on his allotment (usually from a chair with a good book!). I'm a Trustee at our local hospice too.

In 2019 I saw my GP after noticing blood in my stool. The subsequent colonoscopy identified a large polyp which looked suspicious, albeit an initial biopsy suggested it was benign. I then had two further colonoscopies to try and remove the polyp, both of which were unsuccessful. The third time (unlucky in my case) my bowel was accidentally perforated, which made an emergency Hartmann's necessary. Perforations during colonoscopies are a very rare occurrence, so please don't let my experience worry you or stop you having what is usually a routine and very necessary procedure. When it happened, I was awake and so felt it. This made it all the more traumatic. I was also completely unprepared as many of us are for having a colostomy bag.

I'm writing this two years after all this occurred (August 2019). In many ways it feels like a lifetime ago and yet some parts are so vivid and ingrained in my memory that it feels like yesterday. I guess this is part of the rollercoaster of being an ostomate. I like to think I'm generally optimistic by nature and I remember thinking that a RADAR key and being prioritised in queues at the airport were not too shabby silver linings to my circumstances. But in reality, I had some really dark days as I came to terms with my new body, the way it functioned and all the paraphernalia my stoma and bag (Susie) entailed.

The major positive was that I was advised my 7 cm tumour was precancerous, although I did need a further procedure in December 2019 to make sure everything had been taken away and to assess if I was able to have a reversal. So, with much anxiety after my last experience, I wrote Christmas cards on the ward while waiting for the anaesthetist. Thankfully I was able to go home later that day and started to REALLY think about Christmas. It was the first (and probably last) Christmas ever I had all presents bought and wrapped by the end of November in case anything went wrong again in hospital!

Back to the silver linings… I was off work, and so for the first time in years this meant I wasn't doing long hours in the run up to Christmas. Nor did I have on-call commitments, which invariably resulted in missed social events. That said, after coming out of hospital I didn't really want to go out anywhere as I was still recovering mentally and physically. But I did have some lovely times at home with family and close friends, where I felt safest and where I could relax. That was priceless and played a part in helping me get used to my new way of life with a stoma. Shortly after Christmas, I learned I was suitable for a reversal. This was planned for March 2020, but with the pandemic starting just months after my good news, I think you can guess what happened… yes, that's right, it was delayed. Thus I spent Christmas 2020 with a stoma too.

Food and diet are a major part of adjusting to life with a stoma and as the saying goes everyone is DIFFERENT! Throwing Christmas into the mix is yet another consideration. I mean how many people suffer the effects of Christmas food and drink even without a stoma? For me I was too scared to eat nuts (which I love) as I had read so much about blockages and was determined not to end up in hospital again. Would I try them again with hindsight? No. They are a nice to have and not a need to have. And it might sound boring but it really is all about balance – enjoying food, keeping hydrated and, it took me a while to realise this, – relaxing about what you eat. I also think it's important to mention something about not eating too much in one go (we all know what it's like at Christmas and how huge those dinners can get). The dietary guidelines of what effects various foods can have were a really useful reference to me.

To get your copy of our Healthy Eating booklet call 0118 939 1537or visit our website and download.

My first 'stoma Christmas' was spent at my brother's. I prepared a starter of soup, which I knew I was ok with. Let's face it, Christmas dinner is just a fancy Sunday lunch really. Yes, I did have Brussels sprouts, although not as many as usual, and yes, I did provide the family with some interesting music afterwards! Only one person reacted rudely; there's usually one in every extended family, need I say more!! A cure for pancaking was on my Christmas list but unfortunately wasn't delivered. It took me a year post surgery to fully just accept it is part and parcel of having a stoma.

Please call us on 0118 939 1537 to request our advice sheet on pancaking.

Christmas is such a major celebration for many people and comes with expectations, stresses as well as happy times. I guess you could use that analogy for life (and Christmas) as an ostomate too. Some people have a good experience, others have a more difficult time. As for comparing how people's Christmases are – the harmonious family, beautiful food, exciting social events, perfectly behaving stomas - my best advice is DON'T! Do what is good for you on the day and while sharing good and bad times can be useful it's not a competition. Instead, the most important thing of all is to be kind and patient with yourself. I want to also say how much the Colostomy UK Facebook site has helped me with support and advice. If you are facing your first Christmas with a stoma it really is a safe place to ask questions/let-off steam and you are not alone. For me I found it easier to share intimate aspects of how your bowels work with complete strangers rather than your nearest and dearest, but we are all different. I had my reversal surgery in May and so I'm about to enjoy my first Christmas without a stoma for a few years. Who knows, maybe I'll be back next year telling you all how it went! Wishing you and your loved ones a happy and peaceful Christmas.

Christmas cards

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

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

Order form

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

Postage and packaging

Please add the following contribution for card orders of:

Orders up to £5 - £1.50

Orders between £5.01 & £10.00 - £2.95

Orders between £10.01 & £20.00 - £3.75

Orders between £20.01 & £50.00 - £4.95

Orders in excess of £50.00 - £6.50

Number of Packs

Sub Total - £ ____________

UK P&P - £ ____________

Donation (optional) - £ ____________

TOTAL - £ ____________

Personal details

Title: ____________

Name: ____________

Tel: ____________

Email: ____________

Address: ____________

Postcode: ____________

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

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

Paying by cheque

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

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

Paying by card

Card number: ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐ (Meastro only)

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

Signed: ☐ Dated: ☐

Gift Aid Statement:
Thanks to the gift aid scheme – we can reclaim money on your donation from the government. For every pound you give us, we can claim an extra 25p. For example, a purchase of £20 becomes £25 with gift aid, at no extra cost to you. ☐I want to Gift Aid my donation and any donations I make in the future or have made in the past four years. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

Colostomy UK Stoma Aware Survey

We would like to hear from you about how having a stoma impacts on your day-to-day life in the United Kingdom. We also want to know what you think about Colostomy UK and how well supported you feel by healthcare professionals.It's a short survey and should only take 5 minutes for you to complete so please feel free to answer the questions as comprehensively as you like! Your responses will help us better understand what matters to you and will shape the future direction of our campaigns and support services as we shoot for our goal of a more Stoma Aware United Kingdom.

Return your completed survey to: Colostomy UK, Enterprise House, 95 London Street, READING, RG1 4QA.
Complete the survey online instead: www.surveymonkey.co.uk/r/stomaaware

1. Please tell us your gender

☐ Male
☐ Female
☐ Other

3. Please tell us which UK County you live in

____

____

2. Please tell us your age

☐ Under 18
☐ 18-24
☐ 25-34
☐ 35-44
☐ 45-54
☐ 55-64
☐ 65+

4. What type of stoma do you have?

☐ Colostomy
☐ Ileostomy
☐ Urostomy
☐ Mitrofanoff
☐ Colostomy and Urostomy
☐ Ileostomy and Urostomy
☐ other

5. Which year did you have your (latest) surgery?

____

6. How does lack of awareness in society about stomas and the needs of people with them impact on your daily life? (think about peoples attitude, but also things like the built environment - the facilities available in places and the ease with which they can be accessed).

7. Thinking about your experience of the healthcare treatment and support you received both pre- op, and post-op as you recovered and since then (e.g. reviews with your stoma care nurse) what was/is good and what needs to be improved or changed?

8. When you are out and about, using public transport, visiting shops, organisations, visitor attractions, entertainment venues, airports etc. what needs to be improved or changed to make things easier for you as a person with a stoma?

9. Thinking about Colostomy UK, the support and information we provide and our campaigning and advocacy work, what do we do well? What do we need to improve? And what don't we do that we need to start doing?

10. If you would like to be amongst the first to hear feedback from our survey please leave your full name and email address here.

SUPORTX™
MY PROFESSIONAL PERSPECTIVE

Andrew Lodge is a Consultant Orthotist with over 35 years experience. He joined Suportx in 2014 to provide training for the fitting team benchmarking the wide variety of skills within the team against his recognised orthotic qualification. He continues to facilitate the development of both new and existing members of the team as well as providing clinical leadership both within the organisation and to our customers and patients.

There are approximately 200,000 ostomates in the United Kingdom with over 20,000 surgeries performed each year. The age range of ostomates starts from neonates to centenarians, therefore services designed to support ostomates must be designed to cater for all ages.

What Complications often occur with Hernias?

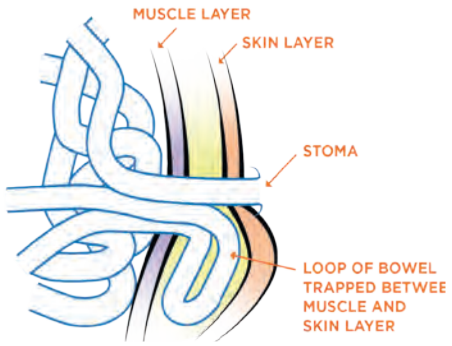
There are known complications that can arise from surgery to create a stoma, one of the most frequently occurring and problematic complications for patients is the formation of a parastomal hernia. Estimates of frequency vary but many consultant surgeons acknowledge that almost all patients who have a stoma for an extended period will develop some degree of herniation.

The risk factors concerning the development of a parastomal hernia are: increased age, increased BMI, smoking, previous hernia repair, emergency surgery, lifting, straining and repeated coughing.

Complications from parastomal hernias can include stoma pouch leakage which is caused by the stoma appliance not fitting well around any resultant bulge, poor cosmesis, pain from the hernia and in extreme cases obstruction or strangulation of the bowel can occur.

What is an effective way to manage Parastomal Hernias?

Other than surgical repair, which is acknowledged to be frequently unsuccessful, management of parastomal hernias will often consist of lifestyle change. One of the most effective strategies in the prevention and management of parastomal hernias is the use of suitable, well fitted support garments.



How can the Suportx Product Range Help with Parastomal Hernia Management?

Suportx offers a comprehensive range of both abdominal and hernia support wear for men, women and children designed to provide patients with an improved quality of life. Appropriate support wear can enable ostomates to enjoy an active lifestyle with the confidence their stoma is comfortably supported during all daily activities.

The range of garments Suportx offers consists of support belts with the unique easy peel fastening system and briefs which is available in a range of differing support levels meaning each garment can be tailored to a patients individual requirements. Suportx recognises that all of their patients are unique and they work to ensure a garment is matched to their own circumstance and body shape.

How does Suportx provide support for Ostomates and Stoma Nurses?

Providing appropriate support wear is about so much more than simply handing out garments. Suportx employs product specialists around the UK who have many years of experience working with patients and support garments. Their role is to assess patient needs and recommend the most appropriate garment from the comprehensive Suportx range.

Suportx work with all NHS Trusts across the United Kingdom. Cooperating with the Stoma Care Nursing teams, Suportx assess patients in a variety of settings. In some NHS Trusts, they run clinics within the hospital meaning patients attend their usual clinic. Alternatively, Suportx fitters also visit many patients in their own homes so they can have the benefit of a full assessment in comfort and privacy.

Inevitably during the recent lockdowns both of these avenues were closed for many patients and Suportx introduced new and creative ways of working such as using the NHS approved “Attend Anywhere” video appointment system enabling video assessment.

attendanywhere®

Recognising that different treatment options work best for different patients, Suportx are continuing to use all options moving forward so patients can choose the option that works best for them.

Suportx offers a first class service and they make sure patients feel comfortable with their choice, all the fitters are: DBS checked, accredited by Consultant Orthotist & Suportx Clinical Director, trained in Health and Safety regulations, GDPR Compliant and wear PPE, Covid-19 LFT twice weekly and are all Covid-19 vaccinated.

What new services are Suportx bringing to the Stoma Market?

Suportx is launching a new end-to-end pathway (*Figure 1*), along with the Stoma Nursing Team, they are committed to making sure all patients receive the best care and support from the start.

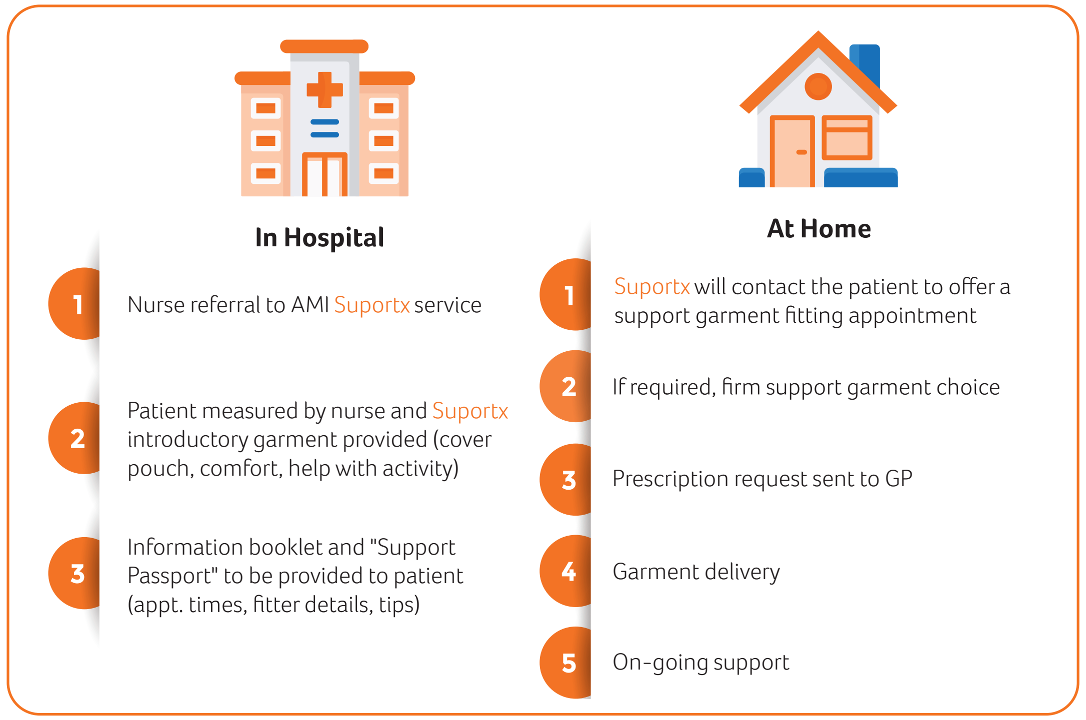
Supporting the ASCN hernia prevention & support guidelines the new service provides every stoma patient with a free Suportx introductory waistband garment and support passport. This enables immediate hernia prevention support and visibility of a specialist support garment fitting pathway.

The stoma care nurse will complete the easy patient referral process to the Suportx fitting service.

- All patients will receive an introductory garment until one of the experienced fitters arranges to see them at home, where they will be shown a range of garments, and with their assistance decide which garment is most suitable for their needs.
- An easy to access custom hospital storage box will be supplied and replenished monthly, containing the following:
    - A full sizing range of introductory waistband garments
    - Patient support service folder
    - Patient support service passport
    - Suportx fitter contact card
- By using Suportx your patients will be confident about moving forward, what to expect next and how to contact for further support.

Suportx products are made from breathable, durable material combined with body-conforming technology. The Suportx anti-roll introductory waistband is purposely designed to secure the abdominal area by staying in place all day and works to help prevent herniation by providing support to the abdominal muscles. The garment flattens the tummy area to reduce the appearance of a stoma pouch whilst also relieving symptoms without restricting the natural flow into the pouch and reducing any ‘dragging feeling’ that can occur. Suportx provides both performance and discretion. Garments can be worn underneath clothing providing adequate support while engaging in physical activities including gardening, walking, DIY, household chores, golf and various other activities.

Suportx™ by AMI Medical can be contacted via freephone on 0800 917 9584 and www.suportx.co.uk



In Hospital

1 Nurse referral to AMI Suportx service

2 Patient measured by nurse and Suportx introductory garment provided (cover pouch, comfort, help with activity)

3 Information booklet and "Support Passport" to be provided to patient (appt. times, fitter details, tips)

At Home

1 Suportx will contact the patient to offer a support garment fitting appointment

2 If required, firm support garment choice

3 Prescription request sent to GP

4 Garment delivery

5 On-going support

Figure 1, New End-to-End Suportx Pathway

Colostomy UK

#ActiveOstomates

active ostomates®

Step Up For Stomas Update

A huge thank you to everyone who took part in Step Up For Stomas this September. We don't have a final total raised at the time of writing, but it's amazing to see how the challenge has encouraged people to be more active on a regular basis. And that includes people like Maggie Wright, who shares her story with us.

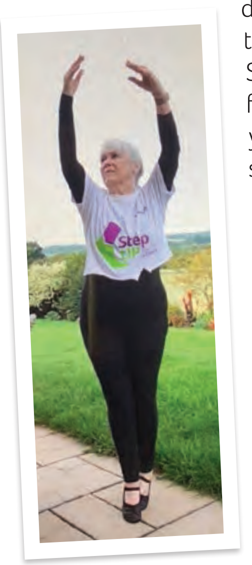
Sport and Fitness After Stoma Surgery

If you're looking to return to being active after stoma surgery, why not pick up a copy of our 'Active Ostomates' booklet? It's full of lots of great tips for exercises you can do at home, and advice around how you can get back to playing team and individual sports.

It also has details of some of the great community activities we provide. If you would like us to send you a copy please email info@colostomyuk.org or call us on 0118 939 1537. You can also download a copy at www.ColostomyUK.org

Maggie's Step Up For Stomas Story

Step Up For Stomas inspired me to imagine walking forever and to think about how my stoma affects my life and the people around me, who cushion me when I fall. By fall I mean having a bad day and fall as in a flare-up, which takes me off track and lies me flat, until my spirit returns and I carry on where I left off.



To walk the thirty days, even if they are a mix of good days and bad, is good. I say: "So what about the bad days - at least I can walk!"

I embraced my solo walk each day with such strength knowing that each step is for a friend out there who will be walking in another time and another town, but still filled with this wonderful energy and love that shouts YES we can still walk.

I have seen my walks as a journey in more ways than one. For me they have also been about sharing my stoma journey, opening up to the world and acknowledging how long my journey has been. My walks have also been for everyone else who has a stoma and lives with the pain and complications that can go with this. That includes, too, the physical and mental pain of acceptance of a bag that is so visible to the wearer. But I'm also walking to remind myself and others that this wonderful bag we have in many cases saved our lives!

My walks have taken me to many places and I have seen so many people I don't know. It has been nice to see the faces of strangers as they look at my Step Up For Stomas top. Sharing the reason for my walks with them and being honest about life with a stoma was uplifting, emotional and inspirational. I planned different walks each day as I tend to get bored with the same route. Some days, I changed the walk for an hour of ballet instead: you are never too old to dance. I started walking in Jesmond Dene Park, Newcastle Upon Tyne. I also made the most of visiting my daughter. Most of my walking was done around the Uttoxeter/Staffordshire area where I live. I kept to mainly flat terrain. I love the hills but felt that walking solo I needed to stay safe and be mindful of my welfare.

My stoma is now four years old and is an established part of me. I know it's there but I don't see it anymore. Two years ago, I had another issue that stopped me in my tracks, a subarachnoid haemorrhage, or bleeding on the brain. The surgeons found three aneurisms. I am now the proud owner of a lovely family… a bag and three platinum stents in my brain, which I refer to as curly wurlies.

Whatever life throws at us it is possible to find a way back, even if the route we take and the time we take differs from person to person. My life changed quickly but I can still walk!

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

Tackling the Stoma Stigma

In the last edition you would have read about the return of our Team Colostomy UK Rugby League team after an eighteen-month COVID-19 enforced absence.

The team exists primarily to help others. It is a way to educate people who are unaware of why someone might have a stoma, or even what a stoma is. The team is also a great way to raise awareness of the impact that stoma surgery can have on people and helps to show to other ostomates that anything is possible when you have a stoma, even playing a tough contact sport.

The team certainly achieved all these goals (or should I say trys!) with their game against Chorley Panthers in September. Full colour features on the team appeared in The Daily Mirror, Daily Express and Daily Star. This was then followed by coverage on BBC Radio 5 Live and the Loose Forward podcast. The story in the national newspapers was even picked up by the international media!

RUGBY LEAGUE

If we can play a full contact sport like RL with a colostomy bag... ANYTHING is possible

THE TEAM BREAKING DOWN STIGMA OF WEARING A STOMA

EXCLUSIVE

Team Colostomy UK are always on the look out for new players and helpers, so if you would like to get involved please email Giovanni.Cinque@Colostomyuk.org

Active Ostomates: at Home

Our Active Ostomates: at Home classes continue to prove popular, with over 200 people taking part in out latest block of sessions via Zoom.

They'll be back again early in the new year, and with activities ranging from chair yoga to Zumba, 80's Dance to Mindfulness, and Art to mat yoga, there should be something for everyone! You can sign up for our 2022 classes online at the following link: www.colostomyuk.org/active-ostomates/

CONQUERING

What Life Can Throw at You

SUSAN JEFFERY

I supported my fiancé Ian in his battle against cancer. We thought he had beaten it, but as we planned our wedding, it returned. It was around this time I became ill. Sadly, we never tied the knot. Ian held on long enough to see me through my stoma surgery and then passed away two weeks after I left hospital.

The pain of what we went through is still ever present, but so too are the memories of being there for one another. I'm sharing my story not to seek sympathy, but in the hope that a reader who is perhaps struggling themselves, will draw comfort from knowing it is possible to conquer the worst of what life can throw at you.

When Ian and I got together in 2007 he was still being treated for a brain tumour diagnosed in 1999. It wasn't until late 2012 that he was given the all-clear. Alas our elation was short-lived. The day after, Ian was told he had non-Hodgkin lymphoma. More chemotherapy followed until he went into remission in 2014.

Susan and fiancé Ian

The plan was to get married in 2015, but while we were on holiday that year Ian fell ill again. This time his liver was the concern. Back home in Wales he spent July in hospital under observation and having tests. With all we had been through my health also suffered and I was signed off work with what was thought to be stress-related illness. This allowed me to stay in Wales and visit Ian, popping back home to Torquay periodically to check my flat and see my GP. At the end of July Ian was diagnosed with liver cancer. It was a secondary cancer and inoperable. The primary cancer was found in his lung. Ian was given six months. We decided to spend what time we had left living in Torquay. The idea was that I would look after Ian at my home and return to work as soon as I was well enough. Part of the 'deal' was that I would drive him back to Wales when he needed to see his consultant.

Over the next two months I felt progressively more unwell, but couldn't pin it down to anything specific, thinking it still to be stress related. Despite this, I was still anxious to get back to work, and with my GP's agreement started a phased return. This proved to be a mistake. After just a couple of days I ended up in A & E, with a suspected kidney infection. Shortly after this episode, I was supposed to be taking Ian to Wales for a scan, but was not fit enough to drive, so he had to struggle on the train. The morning before he was due to return, I ended up back in hospital.

I was in so much pain when I arrived that everything was a blur. I remember giving Ian as my next of kin, before being hurried off for a scan. Later I recall the doctor saying to me that they needed to operate immediately. What I didn't know at this stage was that I had a perforated bowel from previously undiagnosed diverticulitis. A catheter was fitted, and a lady came to ask me where my knicker line was! After telling her, she drew a mark with a felt-tip pen on my tummy which, she said, was to ensure the surgeon put the stoma in the right place. I didn't even know what a stoma was! When Ian arrived, I heard him talking to the doctors, but could register little more than him being told I was very ill and, rather frighteningly, my chances of survival being discussed.

My surgery took nine hours. I came round to find Ian sitting at my bedside in the high-dependency ward, ashen faced and looking terribly ill himself. Stoma care nurses came to my bed regularly (though I didn't know who they were at the time), checking my bag and trying to interact with me, but I wasn't interested. Some days later I was moved to a side room, where I became more lucid. Soon afterwards the oxygen tube was removed, followed by some of the drains and the catheter. This meant I had to get up to go to the toilet. Initially, I had great difficulty walking, but determination won out. I spent my second week in a busy colorectal ward. Here I was visited by the surgeon who told me that my bowel perforating had caused peritonitis and, by the time I was admitted, sepsis had set in too. This was why I was so ill. He also explained how he had removed a section of my bowel and formed a double-loop colostomy.

Ian visited for an hour or so most afternoons, but each time he came he looked more and more unwell. Two afternoons he felt so bad he couldn't make it. I was allowed to leave hospital once I could change my colostomy bag. Ian came to collect me on discharge but was so poorly he couldn't push my wheelchair to the waiting taxi. I know this upset him terribly. Having once been a strapping six-footer of a man, it was just one more indignity cancer imposed on him. We arrived back to my flat on a Wednesday in November 2015 exactly two weeks after I had been admitted.

While I was in hospital Ian had been insistent that he would look after me once I got home. Likewise, before going into hospital I had said the same about looking after him. We both knew that neither was going to be possible now, at least not in the way we had envisaged. Just when we thought that illness could take no more from us, so it did. Ian became very tearful and deep down I think he saw it in terms of having failed me. Of course, this was nonsense, but thinking rationally rarely goes hand in hand with serious illness. Knowing that time was not on our side, we picked ourselves up and made a fresh 'deal'. This was that come what may we would stick together and muddle through together. This was exactly what we did for Ian's remaining days. Ian's health deteriorated quickly. He confessed that when the hospital had told him I might not survive he realised he couldn't manage without me. I think perhaps that this contributed to the speed of his decline. A text he sent to a friend, which I found on his phone after he died, certainly suggests this.

Exactly a week after I came home, I had to call an ambulance for Ian. He was admitted onto a ward in the early hours, and I went home by taxi. Just as Ian had been there for me, I spent the next few days visiting him in hospital and staying with him as long as I could. I was still very poorly myself, but knowing how much his visits had meant to me somehow gave me the physical and mental strength to make the journey several times each day. The nurses on his ward knew what had happened to me and were so kind to us both. Four days after his admission, the doctor called me into a side room to tell me and his brother (who I had phoned with the news of his deterioration) that he was very poorly and didn't have long left. Late on the Wednesday night, exactly four weeks after my surgery and two weeks after I had left hospital, Ian passed away.

> **"I feel I owe it to him to embrace life as fully as possible."**

Ian's brother, two sons, niece and I arranged his funeral in Torquay in early December. Two days later I was allowed to drive, and so set off to South Wales to begin clearing from his rented flat all the things we had accumulated in readiness for our life as a married couple. It was an incredibly difficult four days, not least because I was still very fragile from my operation and numb with the grief of losing him.

I was off work for three months after my surgery. I then returned on a very part-time basis and gradually increased my hours back to normal over the course of a year. Along the way I was (and continue to be) helped by my kind and supportive GP. I've also found great solace from reading Tidings. I've been inspired by others' stories, which in my case have gone a long way towards addressing the sense of isolation I initially felt. I've also been reassured by the help available and the plentiful useful information and tips I've picked up from the pages of each edition. Adapting to life with a stoma has been challenging, but I utterly refuse to allow it to be a barrier to me living. In a way, I can thank Ian for this. I feel I owe it to him to embrace life as fully as possible. I have yet to recover my pre-surgery levels of fitness and I still struggle with depression, but I know that my stoma saved my life and has given me opportunities that were sadly taken from him.

An important message from Ian Daniels FRCS Colostomy UK's Honorary President

Dear readers,

As 2021 draws to a close I am cautiously optimistic that 2022 will be easier.

Working on the frontline in the NHS these past couple of years has been a struggle, with all concerned facing challenges like we have never known before. As a colorectal surgeon I have seen first-hand the impact the pandemic has had on people with bowel disease and stomas. While we can hope that the worst of it will be over soon, COVID-19's effects will continue to be felt for some time. As you will know from reports in the media, there is now a substantial backlog in cancer and elective surgery. This has meant many ostomates are still waiting for reversal surgery and hernia repairs.

There has always been a close relationship between the healthcare profession and charities, but recently this has grown even stronger. As Honorary President of Colostomy UK, I have never felt prouder of the work our charity has been doing during the last two years.

Volunteers on the stoma helpline have helped more than 3,000 people with stomas in the past 12 months. Colostomy UK's new befriending service has provided a friendly voice and a regular link for ostomates who have felt isolated and lonely. Our Active Ostomates virtual classes have helped thousands of people to keep mentally and physically active. Then, of course, there is this magazine. I know what a lifeline Tidings is for stoma patients old and new.

As we move into 2022, Colostomy UK needs your support again. Aside from the medical and social impact on our lives, at Colostomy UK we have to adapt to the current financial trials in society. With your help, we can face the future with confidence and go on doing our vital work. With the long-lasting effects of COVID-19 and the other, more general, challenges facing funding for stoma care, and social care, ostomates are going to need Colostomy UK by their side more than ever.

Please consider making a regular direct debit donation to Colostomy UK. Just £5 a month makes a huge difference. It ensures we can give people the support and information they need, when they need it. This might be as they prepare for stoma surgery, or as they get through those early post-op days or afterwards, when they are more used to the ups and downs of life with a stoma.

You can set-up a regular donation through our website www.colostomyuk.org/donate or by using the form on the opposite page. You can also use the form to make a one-off donation by cheque. One-off donations of by credit or debit card can be made via our website.

Thank you for your help – it means so much to us.

Ian Daniels

Ian Daniels FRCS

Please support Colostomy UK

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

Please complete in BLOCK CAPITALS

Colostomy UK

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

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Postcode*: Phone Number:
Email*: Gender: ☐ Male ☐ Female ☐ Other, please specify:
Date of birth: Date of surgery:
If you are new to **Colostomy UK**, how did you hear about us?
Are you: ☐ An ostomate ☐ A carer ☐ A healthcare professional ☐ Family or friend
☐ Other, please specify: Stoma type: ☐ Colostomy ☐ Ileostomy ☐ Urostomy
Reason for surgery:

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

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

☐ Monthly **Colostomy UK** support e–newsletters
☐ Post from carefully selected third parties (eg about open days or offers)
☐ Emails from carefully selected third parties (eg about open days or offers)

Any other details you would like to share with us

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

ONE-OFF DONATION
☐ £25 ☐ £30 ☐ £50 or other amount (please state) £
☐ I enclose a cheque or postal order made payable to **Colostomy UK**
☐ Please debit my Visa/Mastercard/Maestro Card with the amount specified
Card number (Maestro only)
Expiry date / Security code (Maestro only) Start date / (Maestro only) Issue No.
Signed Date D D M M Y Y

giftaid it **Thank you for your gift**

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

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

Signed: Date: / / 2021

T64

REGULAR DONATION – Instruction to your Bank/Building Society to pay by Banker's Standing Order:
To the Manager: (Bank or Building Society)
Bank Address: Postcode:
Name(s) of Account holder(s):
Account number: Sort code:
I would like to make a regular donation[†] of ☐ £25 ☐ £30 ☐ £50 or other amount (please state) £
☐ monthly ☐ quarterly ☐ annually starting on the ☐ 1st ☐ 15th of the month ☐ Half yearly standing order, year:
thereafter until further notice. (Please cancel any previous standing order in favour of this beneficiary).
[†]Please allow one month's notice to ensure donation processes through banking system and state your donation amount in words:
Please pay: NatWest Bank, Market Place, Reading, Berkshire, RG1 2EP
Account name: **Colostomy UK** Account No: **88781909** Sort code: **60-17-21**
Name: (IN CAPITALS)
Signed: Date: / / 2021

Please fill in this form to make a donation. Check your details are correct, then return the completed form by post to: **Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA.** Telephone: **0118 939 1537** if you have any queries.

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Registered with FUNDRAISING REGULATOR

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To: The Manager

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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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Please Gift Aid this donation and any donations I make in the future or have made in the past 4 years. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year, it is my responsibility to pay any difference.

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

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This guarantee should be detached and retained by the Payer

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

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Colostomy UK

dear nurse

Cath Dixon
Clinical Nurse Advisor
Fittleworth Medical Ltd

Medication and the Effects on Your Stoma

After stoma formation, there may be changes in how your body absorbs medication. In turn this can mean that the medication you take may become less effective as treatment, or not effective at all.

After you have stoma surgery, it is important to discuss any medication you are taking with your GP or stoma care nurse specialist to check if any changes need to be made. It also doesn't hurt to remind your GP that you have a stoma each time they prescribe you medication when you are unwell.

If you have a colostomy, then there should not be many problems, but it is good to remember that:

- Antibiotics may cause diarrhoea.
- Iron tablets may cause black, sticky stools and constipation.
- Painkillers (opiate based) may cause constipation.
- Indigestion medication could cause grey stools.

If you have an ileostomy, more problems could arise with taking medication:

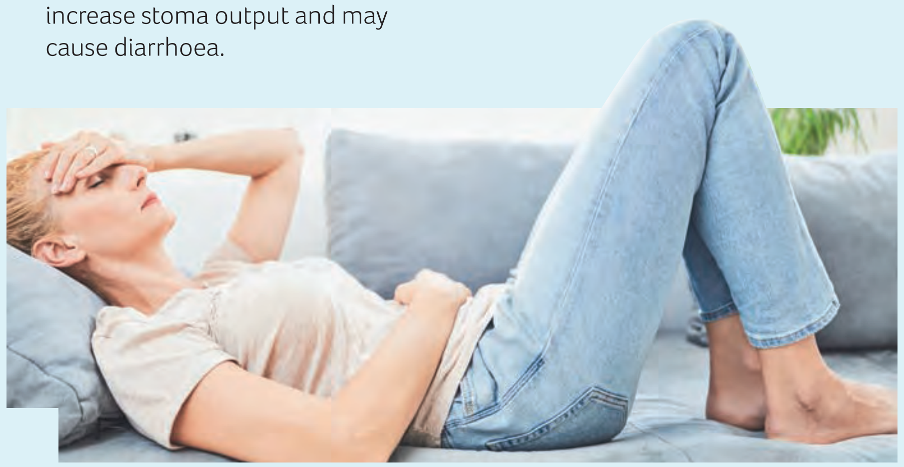
- Antibiotics can change the consistency of your output.
- Iron tablets can cause black, sticky stools and slow down your ileostomy function.
- Anti-sickness tablets can increase the function and change the thickness of your output.
- Medication such as enteric coated (hard, sugary coating), capsules or slow release tablets may cause problems as they cannot be absorbed in the small bowel, so they might be seen whole when you empty your stoma bag. This means that the tablet is not effective in treating the condition that they have been prescribed for. If this occurs speak to your stoma care nurse, GP or pharmacist to have the medication changed. They may switch you to a dissolvable tablet or offer the medication in liquid form. Caution has to be exercised with the latter as many medications in liquid form contain sugars, which can increase stoma output and may cause diarrhoea.

What If you have a urostomy?

If you have a urostomy, there should not be many problems, but some medications can change the colour of your urine:

- Antibiotics - green.
- Warfarin - orange.
- Some antidepressants - blue/green.

If you have any concerns regarding your medication, it is important to speak to your stoma care nurse, GP or pharmacist as they will be able to advise you.



fundraising

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

Supporting Colostomy UK

Every month, dozens of people make the choice to hold an event, take on a challenge, or ask for donations to support Colostomy UK. We are a self-funding charity so without their help we wouldn't be able to support people living with a stoma in nearly as many ways as we do.

Every £1 that you give really does make a difference. This issue features just a few of the people who have supported us recently.

Please consider raising funds for Colostomy UK too, and don't worry… you don't need to even think about climbing Ben Nevis or cycling from Land's End to John O'Groats if you don't want to!

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

Matthew Labuda

Land's End to John O'Groats

On 6 September Matthew Labuda, Chris Lilly, Mark Jackson and Gareth Owen set off to ride 955 miles from Land's End to John O'Groats.

The four friends from Oxfordshire had all cycled together but they had never taken on a challenge this big before. With lots of determination, some very tired legs and invaluable support from Mark's father Derek who drove their support van, they all managed to cover the length of the country in 11 days, finishing their ride on 17 September.

The group were motivated to raise money for Colostomy UK as Matthew's younger brother Nicholas had recently had stoma surgery after a protracted battle with ulcerative colitis. At the date of writing, the group has raised over £5,300, which they happily know will enable Colostomy UK to continue to support people with stomas and their families.

Jennifer Baxter

Jennifer's Lighthouse to Lighthouse challenge

Back in July, Jennifer Baxter walked from Roker Lighthouse in Sunderland to St Mary's Lighthouse in Whitley Bay, covering a grand total of 17.7 miles. She did it because of the support she received from Colostomy UK after a family member had stoma surgery.

Jennifer said: "This is a cause that is extremely close to my heart. There is nowhere near enough awareness of hidden conditions in both children and adults, and they are certainly not understood or accepted as well as they should be. Having a colostomy / stoma is difficult enough without the judgement that comes along with it. The information and advice that Colostomy UK offer is amazing and without it the life of my family, and I'm sure thousands of others, would have been much more difficult."

Jennifer managed to raise over £600 and her story also featured in the national press!

Aaron and Sarah

Aaron and Sarah's Great North Run

'Dad said he would be very proud of us'. On 12 September Aaron and Sarah Nicholls completed the Great North Run for Colostomy UK, raising over £1500 in memory of their father who sadly lost his fight to bowel cancer at just 62 years of age. His two granddaughters (age six and three), also ran the Junior Great Run in his memory.

During his eight-month illness, Aaron's father underwent stoma surgery. "We soon came to realise that [stomas are] something which a lot of people are unfamiliar with." said Sarah.

Clothing Collections

Thank you to everyone who has donated their unwanted clothing and other items to Colostomy UK through our partnership with ICollect Clothes.

Don't forget, if you're planning a clear-out, as well as clothes you can also donate your unwanted paired shoes, linen, bedding, towels and curtains too, and at the same time generate much needed funds for Colostomy UK! They can also collect accessories (bags, belts, hats, scarves), books, DVDs, CDs, soft toys, electronics, and small domestic appliances.

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

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

Thank You

We'd also like to thank the following for their recent support:

Mehal Patel who raised over £300 from his Yorkshire Three Peaks Challenge, Stephen Amstutz who ran the Royal Parks Half Marathon and at the time of writing has raised over £600, Xena Marsha who competed in both the Loch Ness Marathon and the Boston Virtual Marathon, and Shubas Gurang who ran the Vitality Half Marathon.

Picture perfect

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

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

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

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

Legacy

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


Colostomy UK

Help us support the ostomates of today and tomorrow

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

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

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
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Norfolk
NR28 9XH

Colostomy UK

Would you like more?

More news from Colostomy UK direct to your inbox.

More information about the latest stoma product updates.

More opportunities to take part in surveys and have your say on the future of stoma care in the UK.

More access to our support literature and factsheets about all aspects of living with a stoma.

Get more from Colostomy UK by signing up to receive our enewsletters. It's free, and your friends or family are welcome to join too! Visit www.colostomyuk.org/support/colostomy-uk-e-newsletter/ or call 0118 939 1537. www.ColostomyUK.org

Travelling Abroad With a Stoma

CAROL PETERS

Editor's note: Carol Peters was an active 62-year-old, semi-retired teacher, when she found out she had bowel cancer. She also loves to travel. When the opportunity arose for a family trip to Canada, only nine months after becoming an ostomate, Carol was understandably hesitant about going.

In this article, Carol talks about her initial diagnosis and treatment and then how she coped with travel quite early on with a stoma. Her positive attitude and can-do approach to life obviously helped and she gives some useful tips for other ostomates thinking about booking a holiday. If you are planning a trip in the new year, remember to ask for a copy of our Travel Advice booklet and Travel Certificate.

Finding out I had cancer

2012 ended and 2013 started like most other years. We had celebrated New Year with our friends and neighbours and looked forward to a good year. I had retired from full-time teaching in 2010 and was teaching two days a week in a rural Norfolk Primary School. I was fit and well and enjoyed spending time with my grandsons, walking, gardening, and volunteering with Girlguiding.

After a routine bowel screening test in January, I received a letter saying the test had shown an abnormal result. The next sentence which was in bold, "Most abnormal results are not caused by cancer", stuck in my mind. This must apply to me as I didn't have any symptoms and I felt very well. An appointment was made for me to speak to a screening practitioner to discuss next steps. I was advised to have a colonoscopy and the date was set for 20 February 2013. It was only after the procedure, when they asked who was with me, and ushered me into a side room that I began to think something wasn't quite right. I was given the results immediately - they had discovered a tumour in the bowel which was very likely to be cancer.

I decided to tell family and friends and was very grateful for their support. The next few weeks passed in a haze, a whirlwind of hospital appointments, CT scans, MRI scan, blood tests, meeting with surgeons and stoma nurses. I think the worst shock was when I was told lesions had been found on my liver which were likely to be cancerous. The position of the bowel tumour meant I would need a permanent ileostomy and part of my liver removed. The date for my operation was set for 26 March 2013.

The time between my diagnosis and surgery passed so quickly and, although I was nervous and anxious, I was also very positive. The healthcare professionals had all reassured me that I was in a good position as the tumour had been discovered fairly early. Thank goodness for the screening test.

The operation was a success and after a week in hospital I was discharged. My chemotherapy started in May, unfortunately I had a reaction and was back in hospital for a week. Once this was sorted all went well and chemotherapy restarted. I was very fortunate and felt fairly well throughout, I even managed to attend a school residential trip in July!

My first foreign trip as an ostomate

Towards the end of my treatment in October my daughter said the family were going to visit her sister-in-law in Canada for Christmas and New Year and my husband and I were also invited. My first thoughts were: I can't go! I can't make that journey with a stoma, it's too far! What about the weather? What about my diet?

My family persuaded me that it was exactly what I needed so I agreed to speak to my oncologist. His advice was to get some insurance and go! My decision to go was based on several things: travelling with family, staying with family, visiting a country with a good health system, and no language barriers. All I needed was the insurance cover.

Finding good insurance was probably the most difficult thing, after several hours on the phone and the internet, I found Freedom Insurance. They weren't the cheapest, but the person I spoke to seemed knowledgeable about my condition, which gave me confidence that I would be fully covered should I need any treatment while we were away. The next concern was supplies, how much should I take? I took twice as much as I thought I'd need. I decided to give each adult some supplies to take in their hand luggage and divided the rest between our suitcases. I made sure I had a complete change of clothes in my hand luggage. The stoma nurse gave me a leaflet which explained everything in case airport officials asked me any questions. I also booked a suitable meal with the airline. Although I was still apprehensive, once the journey started I didn't have too much time to worry, travelling with a two and four-year old is a wonderful distraction!

On the morning of 23 December, we left at 6am for the drive to the airport. We arrived early only be told at check-in our flight to Toronto had been cancelled, but that there were six seats on a flight to Chicago and we could fly from there to Regina. Because we'd changed flights the airline was unaware of my meal requests. During the first year after my surgery, I was careful with what I ate, as I was desperate to avoid blockages. Hence, I avoided fruit skins, nuts, seeds, and corn. I did wonder if I'd be very hungry by the time we landed but it wasn't a problem. I was still able to choose foods without any repercussions! I was concerned about going through security, but it was very straightforward, and no questions were asked. Just as we were about to take off my daughter asked me if I thought my stoma bag might blow up due to the pressure in the cabin, not the time to ask that, but it did make us laugh! (of course, I now know that this can't happen!) We landed in Chicago intact. After an eight-hour wait we boarded the flight to Regina where Michelle met us for the final two-hour journey to Rocanville.

We arrived at 4 am, almost 24 hours since we'd left home, so I didn't notice too much about our surroundings. Next morning, we woke to a covering of snow. It was Christmas Eve and there was no doubt we were going to have a white Christmas, it felt very magical. Santa popped by on a skidoo. During the first week we went cross country skiing, sledging, skating and curling, all new activities for me. I thoroughly enjoyed the skiing and managed to stay upright. The sledging was fun, but I was more cautious about the skating and curling and struggled to stay upright! The following week we went to Hudson Bay. Nearby Ruby Lake was frozen and we were able to put on snowshoes and walk across the lake.

On returning to Rocanville the adventures continued with a trip down a potash mine, helping to build a quinzee (a Canadian snow shelter), and managing to crawl into it. New Year's Eve 2014 was different to other New Years and was spent celebrating outdoors with a BBQ, fire pit and a glass of champagne in temperatures nearing minus 40C - the lowest they had been for several years. Luckily, we were well equipped with the correct clothing and footwear!

We spent just over two weeks in Canada and just as we were due to leave, we had a text to say all flights had been grounded for several days due to severe weather. I was glad I had brought plenty supplies and as we were visiting family, accommodation wasn't a problem.

The journey home was anything but straightforward.We had to go by car to Winnipeg and stay overnight then fly to Montreal, then Paris, then Eurostar to London and train to Diss. My stoma and I survived the journey! We arrived home just in time to move house the following day!

Would I do it all again?

A definite yes – and I did. I visited India and USA in 2014 and have made several trips abroad since. Would I do anything differently? Not really but my main tips would be:

- Always make sure your travel insurance covers your needs – for example will they reimburse you if you have to make different arrangements to get home?
- Have plenty supplies delivered before your holiday – if you're worried about taking supplies and extra luggage speak to the airline before you travel.
- Book an aisle seat for easier toilet access!
- Consider changing your bag at the airport or before long journeys by coach, train or car.

The first trip was definitely the most daunting and the fact I was travelling with family and visiting family gave me more confidence. My advice – plan ahead and go for it. If you're concerned, try a short trip first. Good luck and enjoy your travels.

Stay warm with Colostomy UK!

Our **hooded sweatshirts and beanies** are available to buy via our shop!

These cosy hooded sweatshirts are £31.99 and available in **grey, purple and pink**. The sizes are available in **Small** to **XXXL**.

Acrylic / Cotton / Polyester mix
features embroidered Team Colostomy UK logo
on front and #ActiveOstomates on back.

Our beanies are £9.99, **one size fits all** and are available in **purple.**

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

Stomas and Hydration

POOJA DHIR

Pooja Dhir
Specialist Dietitian
City Dietitians
Instagram @dietitian_poojadhir
Email- pooja@citydietitians.co.uk

Earlier this year I gave a virtual talk to Cambridgeshire Ostomy Group Support about staying hydrated when you have a stoma. Giovanni from Colostomy UK was there and thought that Tidings readers would benefit from seeing the questions that were raised and my answers.

If you are unsure about your diet and/or stoma it is definitely worth contacting your NHS dietitian, or a private practice dietitian such as myself who specialises in colorectal conditions and surgery, to support you.

Q1. Does water/ too much water lead to dehydration?

A. The type of fluid is most important if stoma output is high. A high stoma output is considered to generally be greater than 1200 millilitres. As a guide, this equates to about 4-6 bag drains or bag changes a day, with output of a consistency that is looser than normal. If your output is high you may need to limit your intake of hypotonic fluids such as water, tea and coffee to one litre/day and sip one litre of Dioralyte/ St Marks solution (available on prescription) throughout the day. You should avoid having this an hour before or after meals, as it can rush food through the stomach. In general, when stoma output is normal (within 'normal range' dependent on type of stoma), it is important to ensure normal hydration through water, along with a variety of other drinks such as juices and squash, to support hydration and body function.

Q2. Foods to avoid with a stoma? Help with blockages?

A. There are no foods to avoid with a stoma, although if it is a new stoma, it is advisable to avoid fibrous foods e.g. nuts, seeds, pips, sweetcorn, pineapple, and vegetable skins for 6-8 weeks to allow the body and stoma to settle. Once the stoma is settled, gradually introduce these back in small quantities. Caution should be exercised when eating skin from fruit and vegetables as these are higher in fibre and contain cellulose which is not digested by the body so can increase the risk of blockages. Another tip to reduce the risk of blockages is to make sure you always chew your food properly to support digestion. Higher fibrous foods are more difficult to digest, so depending on how your stoma is, consideration should be given to reducing these. Try to speak to a dietitian before making dietary changes.

To help with blockages, if your stoma stops working, stop eating but continue drinking fluids. Try drinking three glasses of water, rest and massage the stomach/stoma area. If this does not work, try again in an hour's time. If your stoma continues to remain inactive you should contact your GP or stoma care nurse.

Q3. Are there any nutrients not absorbed after you have had stoma surgery?

A. Most nutrients should be absorbed, however it does depend on what surgery you had, how much of your bowel remains and what part of the bowel. Generally, salts, water, magnesium, and potassium may be reduced in absorption if the stoma output is high. Any losses should be managed through diet and medical management. Your nutrient levels can be assessed by having a blood test and then monitored and treated by the medical and dietetic team

You may be advised to take a multivitamin to support a balanced diet to ensure you get the vitamins and minerals you need. It may be worth considering liquid versions of these if tablets are not well tolerated. Vitamins and minerals are absorbed higher up in the small bowel and therefore should have adequate time in contact with the bowel wall to be absorbed. If you are concerned about your diet/nutrition it is worth consulting with a dietitian to discuss it in more detail.

Q4. How can you reduce air/gas in the stomach?

A. Gas is a normal product of digestion but can be increased by swallowing air whilst you are eating or by eating higher fibre foods. Ways to reduce the gas include:

- Take time to eat and chew your food well.
- If you are having a fizzy drink, pour into a glass and leave to stand for five minutes before drinking.
- Avoid having drinks through a straw.
- Avoid chewing gum.
- Try lower fibre alternatives, e.g. white breads, cornflakes.
- Reduce pulses in your diet.
- You can try peppermint oil, although its benefits are not well evidenced.
- Try lying down on one side and then the other to see if it is positional.

Q5. Probiotics with no colon (ileostomy)

A. Probiotics are 'live' microorganisms that help with gut flora/gut microbiome. They are normally absorbed in the colon, however are also found in smaller quantities in the small intestine. There is limited evidence about the benefit of probiotics when there is no colon, however there is also no evidence of adverse effects. It is therefore individual preference whether you try it. If you do, I recommend a multi-strain probiotic.

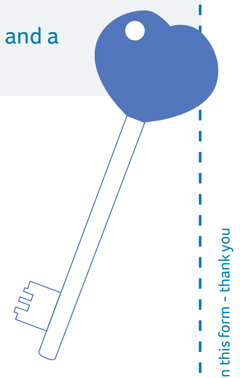
Q6. Medication for high output ileostomy?

A. There are various medications that can be prescribed to treat a high output stoma, these include Loperamide and Codeine Phosphate. These are normally started on lower doses and managed alongside dietary changes, e.g. a low fibre diet, fluid restriction, double strength Dioralyte/ St Marks solution. Once the stoma is settled, normally the doses of medications are gradually lowered, and the stoma output monitored. It is important to try and reduce the stoma output to less than 1200mls to reduce the risk of dehydration and malnutrition. Your stoma care nurse team and dietitian should be involved in supporting with this. It is helpful to have input from a dietitian if your stoma output is high as they can provide individualised advice on diet and nutrition and provide therapeutic management. If you are concerned about taking these medications then speak to a healthcare professional.

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

Ensure you always have access to a toilet by purchasing a Radar Key and Photo ID card. Through the with the National Key Scheme, Radar keys open the doors to over 9,000 accessible toilets in the UK in places like shopping centres, pubs, cafes and department stores. A Colostomy UK Photo ID card, which is endorsed by Disability Rights UK (and displays 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 Photo ID card you will need to include a copy of your prescription or delivery note as proof of eligibility and a passport sized photo.



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

Title: ______________________

Name: ______________________

Tel: ______________________

Email: ______________________

Address: ______________________

____

____

Postcode: ______________________

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

Signature (or carer signing on behalf of the person name above): ☐ Date: ☐

Please **tick** as appropriate:

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

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

Return all required items to: **Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA. Cheques should be made payable to Colostomy UK.** For payment by credit card, send your documents in the post with a contact telephone number, we will then call you to take a card payment when received. (If you have any queries or would like to pay by credit card, please contact **Colostomy UK** office: **0118 939 1537** or **info@ColostomyUK.org**).

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

Colostomy Irrigation and You DVD

Order Form Colostomy Irrigation and you (Patients)

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

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

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

Colostomy UK, Enterprise house, 95 London Street, Reading, Berkshire, RG1 4QA
or you can purchase online at: www.ColostomyUK.bigcartel.com

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

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

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Expiry date: ☐☐/☐☐

Security code: ☐☐☐

Start date: (Meastro only) ☐☐/☐☐

Issue No. (Meastro only) ☐☐

Signed: ☐ Dated: ☐

Please allow 30 days for delivery.
Colostomy UK, Enterprise house, 95 London Street, Reading, Berkshire, RG1 4QA | Charity No. 1113471 | VAT No. 917079312

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

My 'Bag for Life'

CHRISTINE WRIGHT

I'm Christine, 76 years old, and a great advocate of recycling, and avoiding waste etc. However, I never imagined I'd end up with this particular 'Bag for Life'!

How it all Started

After a few months of ambiguous symptoms, which I ignored (lesson learned – don't ignore anything unusual), I started with rectal bleeding and thought I'd better get myself to my GP pronto! After an examination, off I go to have a colonoscopy. "Sorry Christine, but you definitely have a cancerous rectal tumour." Wow! With little time to get used to the idea, it's off for MRI and CT scans, then to see a colorectal consultant. Still in hit-over-the-head mode, I'm dealing with this fine, even when told that my only realistic option is surgery to remove my tumour, together with the entire rectum (who would have thought such a thing happened!) and a colostomy. Ok, better than the alternative I thought, and at least it seemed probable there would be no need for either chemo or radiotherapy.

In the three weeks between seeing the surgeon and the operation, I swung from cheerful optimism to panic about dying and leaving my husband, children and grandchildren behind. But when I started planning selling the house so my hubby could manage without me, and looking at funeral packages, he said "Whoa! Let's take this one step at a time." Quite so, I stopped my rapid rush into overdrive and vowed to take things as they came.

Surgery

There was a moment of blind panic the morning of surgery, never having been in hospital before apart from childbirth, and with no experience of an operation, or even having been ill really. But my surgeon and anaesthetist put me at ease, and I woke up seven hours later in a hazy state. No pain, I had been given an epidural as well as anaesthetic.

Aftershock

But next morning – ouch! My surgeon came to see me and I asked him why he'd let a herd of elephants stamp over me when I was asleep. Honestly? I felt pretty grotty after my op. As well as multiple holes in my extremely tender abdomen, and a very sore bottom end, there was this weird, alien thing on my stomach. I felt stiff and achy, and every one of my aged years. Then, after being dragged unwillingly by the physiotherapist to stagger painfully down the corridor, in came my stoma nurse. Putting on a brave face, I took off my first bag and was shown how to clean and change everything and replace it. Ah, that's so easy with an empty bag – when you get the first 'delivery' it's a whole different story! More about this later.

The Slow Crawl

Luckily, although in the middle of the Covid lockdown, my hospital had just started to let one visitor in for an hour a day. Thank goodness my frantic and worried husband could come in and see me. He gave one day up for my daughter to visit (who promptly burst into tears at my pale and wan face and wobbly stance). I was so pleased to see them and thought of all those people who'd been in hospital during the Covid peak, with no visitors at all.

I must have put on a good act at being totally in control and coping well, as I was thrown out on the fifth day, much to the horror of my husband, who wasn't prepared for this early release. Although a little anxious at having to cope without the kindly staff and stoma nurse, I was euphoric to be in my own home and my own bed (alone, as hubby was relegated to the spare room as I was rather sore). Sitting and even lying in bed was a trial due to my various sore regions, but we soon found comfortable positions with multiple cushions and memory foam. Hubby prepared me small but tasty nourishing meals, I slept every afternoon like an old person, and we went for a daily 'toddle' round the block for my enforced, slow, exercise. Family and friends visited. The days settled into a routine of getting up, taking at least an hour to shower, dress and do the necessary bag-changing and stuff, eating, afternoon naps, dinner, walk and early bedtime.

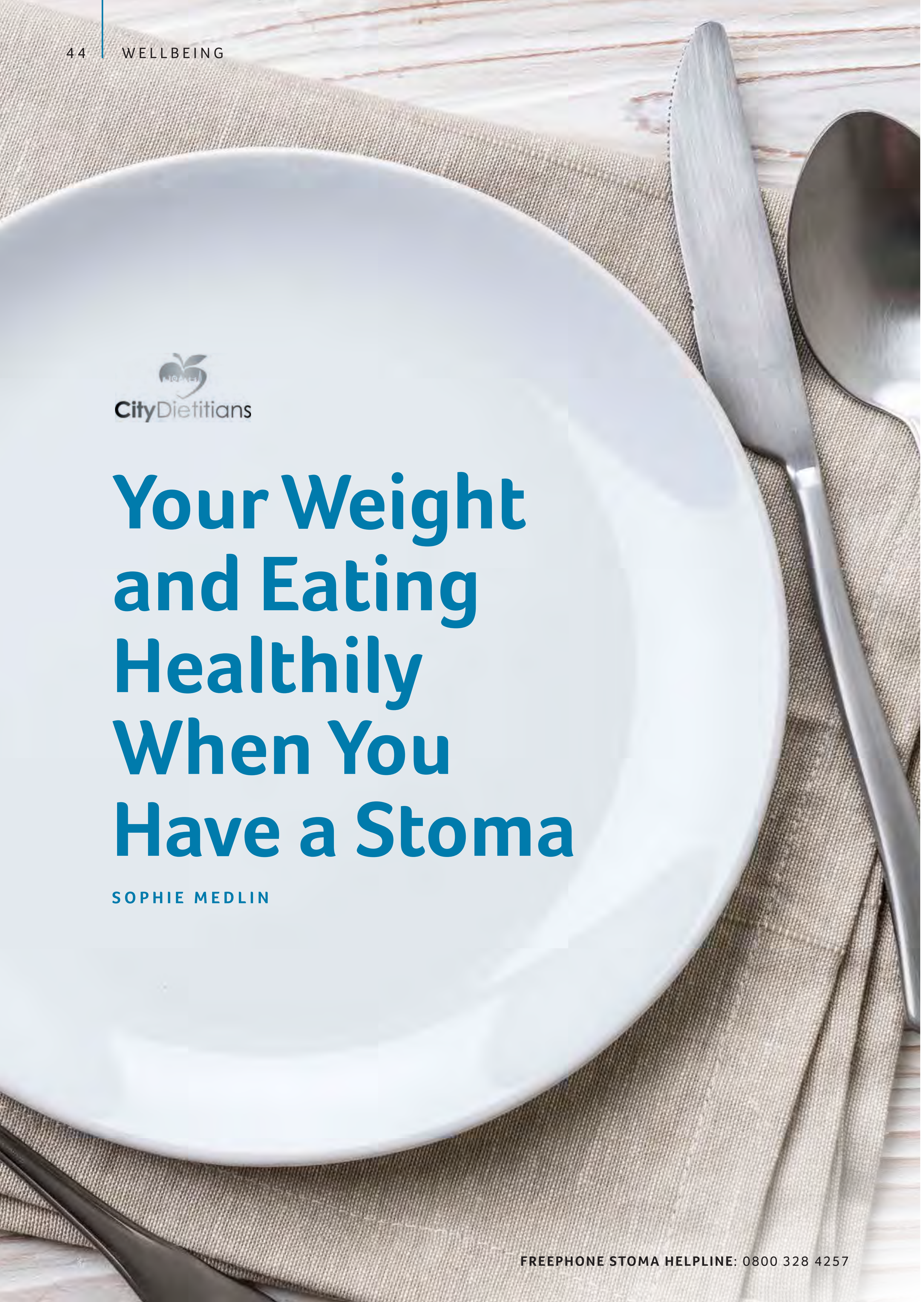
There were a few challenges with my stoma and bag. Suffice to say I am rather squeamish and found the whole process daunting. I'm sure some readers can identify with this! But with the aid of a Covid mask covered in Vic (that stuff your mum used to rub in your chest when you had a cold), that hurdle was overcome. I have very sensitive skin and it took some experimenting with different bags, wipes, powders etc. before everything settled down round my stoma. I was often uncomfortable, itchy and sore. My rear end took a while to heal but got there eventually. A few op scars took a while to heal too, but again, they got there in the end. So finally it all settled down, and with the bonus of some little stoma bag covers my lovely sister made me from soft pillowcases (definitely make your own – bought ones are not always very soft), it all became much more comfortable.

Up and Running

Over the weeks, I got my mojo back, and wanted to be in the garden doing stuff (although hubby confiscated anything heavy!). Gradually I took back the cooking (relief all round here), took longer walks, started planning some trips and generally getting on with life again.

As I write this, it's five months since my surgery, and I can honestly say I feel great! How lucky am I? OK, a pretty radical op, with several bits removed, and one bit added to my anatomy. But no chemo, no radiotherapy – and hey, I'm still here. My 'Bag for Life' is part of me now, just a small bit of my daily routine. We've been for a few short breaks to visit family and friends, and a couple of sleepovers. We have several bigger trips planned for the near future. I recommend the Colostomy UK travel advice booklet; it contains excellent information and advice. My lovely family and friends have been fantastic and very supportive, and my hubby and I have just completed the 5k Race for Life for Cancer Research UK (more of a walk in our case), but we're delighted to have raised over £1,200.

My mottos are:
Stay positive, be brave, soldier on, and count your blessings!



CityDietitians

Your Weight and Eating Healthily When You Have a Stoma

SOPHIE MEDLIN

Sophie Medlin
Director and
Specialist Dietitian
City Dietitians
Instagram @sophiedietitian

Losing weight can be difficult when you have a stoma. After surgery many people change their diet in an effort to control their output. This can lead to weight gain. Sometimes too, having a stoma can affect a person's body image and self -esteem, leading to emotional eating. There are many reasons for keeping your weight in check. Gaining weight following stoma surgery can lead to stomal retraction and hernias, which can cause complications fitting devices and may require surgery.

A good way to assess if you need to lose weight is to check your Body Mass Index (BMI). The NHS has a tool for this: www.nhs.uk/live-well/healthy-weight/bmi-calculator/. Just bear in mind that some people may be naturally lighter or heavier than the scale recommends. If you are unsure if you are a healthy weight, ask your GP or stoma nurse.

There is no easy solution to losing weight. Despite what you read in the media, the only way to successfully manage your weight is by making small lifestyle changes. This means making healthier food choices and more physical activity. Fad diets might reduce weight quicker, but keeping it off is a different matter. It sometimes seems that all 'healthy' foods are high in fibre and can cause unwanted side effects. While high fibre foods are good at keeping you fuller longer, they are not the only way to reduce weight. Hence, people with stomas can reduce their weight without adverse consequences.

A balanced approach: Your diet should be well balanced and include a wide variety of foods from all food groups. Making small changes to all the food groups can help reduce weight gradually and keep the weight off. You might start by reducing your portion sizes (apart from vegetables).

Starchy foods such as bread, rice, pasta and potatoes:

Many people rely on starchy foods to regulate their output. If you are one of them, then choose a starchy food with each meal, as they are filling and low in fat. But beware of adding butter or spread, creamy sauces or oils to starchy foods, as this will increase their calories. Remember too, that starchy foods which have been cooked, chilled and then heated, e.g. ready meals, pasta and rice salads or reheated food from previous meals, become 'resistant starches'. This makes them difficult to digest and liable to cause bloating and increase stoma output.

Milk and dairy foods: Try to eat calcium rich foods such as dairy produce every day. However, some dairy foods can be high in fat, which can promote weight gain. Choose low fat dairy produce such as skimmed milk and lower fat cheeses and yoghurts to help reduce fat and calories in your diet to aid weight loss.

Foods and drinks high in fat and/or sugar: Things like crisps, biscuits and cakes are foods we don't need nutritionally but are an important part of celebrations. It is fine to include these occasionally, but they become a problem when we eat them daily.

Meat, fish, eggs, beans: are excellent sources of protein, which are essential for good health. Women should have two portions per day, and men three. Again, choose lower fat options. Lean meat with all visible fat trimmed off will help to control your weight.

Fruit and vegetables: are excellent sources of vitamins and minerals, and most are low in calories and fat. Unfortunately, their high fibre content can make them more difficult to tolerate when you have a stoma. Peeling fruit and vegetables and cooking them well can help. Try soups and smoothies to give your vegetable and fruit intake a boost. There is no reason why as an ostomate you can't have your five-a-day, you just need to make some sensible adjustments.

If fruit and vegetables cause you a problem, you may find it difficult to choose healthy snacks.

Here are some low fibre, low calorie snack ideas to keep you going in the afternoon:

- Cracker breads or rice cakes with Bovril/Marmite or extra light cream cheese
- Low fat yogurts
- Cup-a-soups
- 2-3 Rich Tea Fingers
- Sugar-free jelly

Fats: There is much written about healthy and unhealthy fats. While it is important to be aware of the types of fats you consume, from a weight loss perspective it is good to remember that all fats gram for gram have the same amount of calories. This means that butter has the same amount of calories as olive oil. If you want to lose weight, all fats should be consumed in lower quantities.

Alcohol: is very high in calories, which have no nutritional benefit. Be aware of the extra calories you could be consuming from alcoholic beverages. On average a pint of bitter contains 170 kcals, a small glass (125ml) of white wine 85 kcals, a small glass of red wine 82 kcals and a 35 ml measure of spirits 117 kcals.

Portion size: Perhaps your diet and stoma output are in delicate balance and, although you want to lose weight, you are worried about making any changes because of the risk of unwanted side effects. Maybe instead you feel you are eating the right things and are still not losing weight... Reducing your portion size is a fool proof way of reducing your calorie and fat intake, helping weight loss.

Here are some tips to getting portion in perspective:

- A portion of cheese is a small matchbox sized piece – around 30g.
- A portion of meat should be roughly the size of the palm of your hand – between 60-90g depending on your size and build.
- Check food labels, the calories and fat may be listed as per 100g, not per portion.
- Try a smaller plate – a side plate may help you to control your portions.
- Measure out fat and oil to keep the amount you use under control.
- Eat your food slowly and chew for longer, this helps you feel fuller quicker.

Physical activity: is helpful in weight management and will burn calories and promote weight loss. It also has other health benefits. If you are considering taking up a new exercise regime you should discuss this with your healthcare team. Many GP surgeries now offer 'exercise on prescription' schemes, which give you the opportunity to increase your physical activity levels in a safe and controlled way.

Excellent sources of further information include:

- The Foods Standards Agency: www.food.gov.uk/
- The National Health Service: www.nhs.uk/ search 'healthy eating'
- The British Heart Foundation: www.bhf.org.uk search 'healthy eating'
- Colostomy UK's booklet: Healthy eating: Nutritional guidelines for people who have a stoma. Visit the Colostomy UK website www.colostomyuk.org to download a copy or call 0118 939 1537 to ask for a copy to be sent in the post.

Your Letters and Emails

Editor's note: Thank you to everyone who has been in touch. Here is selection from the mail bag. If you have time over Christmas to drop me a line please do!

Editor: I received a letter from Mr S advising his wife had passed away, but wanting new ostomates to know a little about her life with a stoma:

"Mary was given three months to live in 1975, but survived and in 1978 had a very advanced operation at the time, and had her life saved, by receiving both a urostomy and a colostomy. [afterwards] She carried on working and continued to look after the young children… within a short time we resumed family holidays [including] driving to France and air travel.

Mary lived with her stomas for 43 years and even though there were accidents and embarrassment, she led a normal and happy life."

Dear Editor,

Hi,

Just finished reading the interesting article on Eric Douglin (autumn 2021) and I am not surprised that more people from the BAME community do not come forward to tell their stories. Prejudices are still prevalent in today's world and maybe they do not want other people to know that they have a disability, as well as being someone of colour or different origin.

He should be proud of himself for coming forward and telling his story.

It brought back many memories as on 1 September this year I will be thirteen years post cancer and thirteen years of wearing a colostomy bag and apart from very close family and friends nobody is ever told I wear a colostomy bag.

Especially as the job I do can be very stressful and physical at times and as a black person I am a minority in the company I work for of over a thousand staff.

I A

Dear Editor,

L.W. of Hampshire's letter in Issue 63, gives invaluable advice on the use of stick-on filter seals to avoid pancaking. In my case I calculate that doing this when I was using a one-piece bag saved the NHS at least £1,000.00 a year by reducing the number of pouches I used. When I became a colostomate 12 years ago my induction to stoma management made scant reference to this vital little product. The advice I received was confined merely to its application to prevent water from entering the pouch while swimming or bathing or to save the embarrassing escape of gas on social occasions. Over the following years I was glad to discover its versatility in fulfilling a variety of additional needs.

Particularly welcome has been its contribution in allowing me to be follow a dietary course unconstrained by lists offering advice on gas-producing items to be avoided. Thus, I can indulge myself with lager, baked beans and spring onions etc, as much as I please, secure in the knowledge that all I have to do, when pressure demands, is to retire to a quiet spot, peel back the convenient little sticker, gently express most of the gas, then re-seal, leaving just enough in reserve to avoid any risk of pancaking.

During the recent heatwave I experienced an unwelcome series of sub-baseplate leaks. Here again the little sticker came to my rescue in another guise. Like the traditional canary in a coal mine it served to alert me, through the sudden deflation of my pouch, to the absence of gas (unlike its mining counterpart who warns of its presence), indicating a likely subterranean leak. This served as a signal to me that it was time to investigate the need for a change of baseplate. In this connection I might usefully add that one of the main reasons I converted from the one-piece to the two-piece system in recent years was precisely in order to enjoy the benefit that the latter tends to have in reducing the collateral damage caused by occasional leaks by giving early warning of an impending event. I found with the one-piece pouch leaks tended to happen without much prior warning. At least that has been my experience and I am glad to have made the transition.

Michael Ward, Cambridge

Yes I have a stoma

By Carole O'Ryan

Yes I have a stoma
It sits upon my tum
At first I really hated it
But now it is my best chum

Yes I have a stoma
It doesn't show or smell
And when I'm dressed and going out
No-one will ever tell

Yes I have a stoma
I swim, I dance and travel
At last I feel quite free
My pouch and I do what we want
And that feels great to me

Yes I have a stoma
And sometimes when I'm out
It makes me laugh to see
Advertised "bag for life"
And I want to shout
– "that's me!"

Dear Editor,

In the latest issue of Tidings you said you were wondering how people have found coming out of lockdown. I would say quite worrying and it has made me more anxious than being in lockdown. Some people may be surprised by this. I was but am sure I will soon adapt again.

I have had a stoma for ten years and the last eight I have managed it by irrigation. I found the restrictions of movement and meeting people gave me a much more settled and structured approach to coping with my stoma. I didn't have to worry if I thought I wouldn't have time to irrigate properly which often resulted in disastrous episodes. I have not been going away so didn't have to worry whether I would find the facilities I need. Being more relaxed meant irrigation was much more efficient, and I was able to have a more regular routine. During lockdown I have eaten better and enjoyed regular exercise which has improved my general health and well-being.

Mentioning irrigation, I have missed the articles on this subject. I don't know anyone personally who irrigates so found them very helpful. I hope we might have something again.

Congratulations on a splendid magazine.

Liz, N Yorkshire.

Dear Editor,

The article (autumn 2021) into the effects of having a stoma as a child was brilliant. I had mine aged five and am now 66. The report is very accurate on the effects having a stoma has had on my whole life, the part about school not being able to concentrate not wishing to go to school. The stress was dreadful and in those days the bags were not odour proof, the toilets were not great, and no stoma nurses to help. It has made me strong in some ways, but the overall effect has limited my social skills as I was told not to tell anyone about my stoma.

The thing that upsets me is people saying: "oh that was then, get over it", but I never have. Don't get me wrong I worked on and off all my life, dated, married, and had two sons, now five grandchildren who are not allowed by their parents to know I have a stoma (more secrets).

So thank you for this article I am lucky enough to know a couple of people older than me who I can relate to, who also had stomas as young people.

Once again Colostomy UK and Tidings giving a voice to people living with a stoma.

B

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:

Admin line: 08118 939 1537 | **Email:** info@ColostomyUK.org | **Website:** ColostomyUK.org/information


Active Ostomates sport and fitness after stoma surgery


Campaigns and Projects Flyer


Caring for a person with a stoma


Caring for a person with a stoma and dementia

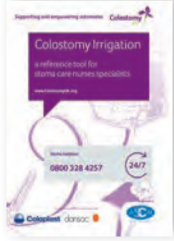

Colonoscopy through a stoma

Fundraising Pack


Healthy Eating


Helpline Cards


How will a stoma affect me?


Irrigation Booklet


Irrigation DVD (nurses)


Irrigation DVD (patients)

Legacy Flyer


Living with a stoma


One to one


Ovarian Cancer and stomas


Pain and discomfort


Parastomal hernias

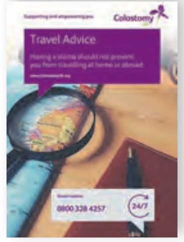

Rectal discharge

'Sam has a stoma' colouring book

Stoma friendly toilet guideline and stickers


Stoma reversal

Tidings magazine


Travel advice


Travel certificate

Tri-Charity leaflet


Welcome pack

News from Support Groups across the UK

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

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

Tel: **0118 939 1537** or e–mail: **info@ColostomyUK.org.**

King's Lynn & District Ostomy Support Group - We're Back!

King's Lynn & District Ostomy Support Group meets quarterly at the Reffley Community Hall in King's Lynn (PE30 3SF).

The Group covers North & West Norfolk, Cambridgeshire & Lincolnshire and is run by colostomy, ileostomy and urostomy patients for patients, their families and friends. Informative talks on health-related matters of interest are given by both healthcare professionals and guest speakers. Refreshments and a raffle are provided.

We provide a patient-to-patient forum for members to meet up and share their support and tips in a friendly, informal environment, to encourage wellbeing and regain self-confidence.

We are delighted to announce that meetings will resume in March 2022, subject to any applicable government regulations, with the full schedule below:

5th March 2022
11th June 2022
3rd September 2022
3rd December 2022

Meetings are between 2-4pm and are usually held on the first Saturday (June 2022 has been moved in recognition of the Platinum Jubilee bank holiday).

We look forward to seeing our friends and group members, both old and new, in the New Year - come along and join us!

Please telephone a member of the committee for further information:

Elspeth Hardy: 01553 775698

Mary & Chris Thompson: 01406 363756

Mo Ford: 01263 712143

Christine Spicer: 01553 674962

Open Days

Stevenage Ostomistics

Saturday 26 March 2022 from 10am to 1 pm

Location: The Oval Community Centre, Vardon Road, Stevenage, SG1 5RD

You will be able to talk to manufacturers and distributors and listen to a short talk by a dietitian and stoma care nurse about skin care. Refreshments will be available, and we would love to see you there. There is ample free parking and Bus No.2 to St Nicholas departs every 12 minutes from Stevenage bus station and stops at The Oval.

For further information about the day or Stevenage Ostomistics Support Group, please contact: Judy Colston: **01438 354 018** or email **neilcolston@btinternet.com**

Channel Islands

Guernsey

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

Jersey

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

England

Berkshire

E.B.O.C (East Berkshire Ostomy Club)
Jackie Dudley T: 01344 426 652
Reading Bowel Cancer Support Group
Ted Wingrove T: 0118 961 8297
or 07974 790 558
WAMS (Windsor, Ascot, Maidenhead & Slough) Stoma Support Group
E: wamsstoma@gmail.com
T: 0118 939 1537

Bristol

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

Buckinghamshire

High Wycombe Stoma Support Group
T: 0800 318965
Milton Keynes Stoma Support Group (MKSSG)
Morag Harvey (Secretary)
E: mkssg.sec@gmail.com
T: 07843 768 386
You Are Not Alone Stoma Support Group - Chesham
Carla T: 07846 354 918
E: carlawright0502@gmail.com

Cambridgeshire

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

Cheshire

Countess of Chester Hospital Stoma Support Group
Stoma Nurses T: 01244 366 170
Crewe & District South Cheshire Stoma Group
Venue phone number: 01270 560 471
Stockport Support Group
Marion Caulfield T: 0161 320 9400 or 0800 652 6667

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

Co. Durham

Bishop Auckland Stoma Care Group
Mrs Maureen Davison T: 01388 818 267
E: rdavison816@gmail.com
Darlington Support Group
Margaret Clothier T:0191 333 2184
Durham Stoma Support Group
Lynn Ridley, T: 0191 333 2184

Cornwall

Cornwall & Plymouth Bowel Cancer Support Group
The Secretary T: 01872 241 145
E: cbcsginfo@gmail.com
W: cornwall-bowel-cancer-support-group.co.uk
Lanhydrock Ostomist Group
Mandy Rowe T: 01726 832 642
E: murphy.rowe781@btopenworld.com
Henry Kendall T: 01208 850 986
E: h.kendall380@btinternet.com

Cumbria

Grange Cancer Support Drop in
Marie O'Connor T: 01539 533 279
Stoma Support Groups in North Cumbria
Stoma Care Nurses T: 01228 814 179

Derbyshire

Diverted Local Stoma Support Group
Diana Manning T: 01283 541 311
F.I.S.H.Y.S. (Friendship, Information, Support & Help for Young Ostomates (age 18-45)
E: fishysderbyshire@gmail.com
Mercia Inside Out Stoma Support Group
Sally Chester T: 07500 441 442
Jackie T: 07919 002 612
Gary T: 07779 218 245

Devon

Devon IA
E: devon@iasupport.org
Mid Devon Ostomy Support Group
Janice E: janice234ford@gmail.com
T: 07923 975 051
Plymouth & District Bowel Cancer Support Group
Rita T: 0785 557 1840
E: admin@plmdistbcsg.com

Dorset

Colostomy Urostomy Pouch Ileostomy of Dorset - CUPID (Bournemouth)
Beryl Andrews T: 01202 483 303
Colostomy Urostomy Pouch Ileostomy of Dorset - CUPID (Poole)
Jenny Pipe T: 01202 740 440

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

Essex

Connect
Lin Hart T: 01279 505 273
E: comeconnectwithus@gmail.com
Mid Essex Stoma Support Group
Paul Foulger T: 01245 224 374
N.E.S.S (North Essex Stoma Support)
Brian Waller T: 01206 540 449
Optimistic Ostomates
Angela Taylor T: 01702 385 510
Redbridge Ostomists Club
Stoma Nurses - Chris / Lisa
T: 020 8970 8321
STEPS - Stoma Essex Patients Support
T: 01268 451 937
E: stepsessex@gmail.com

Hampshire

Solent Ostomates Support Group (S.O.S.)
T: 07527 707 069
E: solentostomates@hotmail.co.uk
Southern Ostomy Group
Caroline or Karen T: 07756 819 291
E: southernostomygroup@hotmail.com
The Hampshire Ostomates Support Group
Nicki Beare T: 07771 558 458
E: Hampshireostomatesgroup@gmail.com
Waterside Stoma Support Group
Hazel Derham T: 023 8089 1934
E: juderhay@outlook.com
Wessex Urology Support Group
Mrs Jo Stacey T: 07910 786 978

Herefordshire

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

Hertfordshire

Ostofriends Stoma Support Group (Potters Bar)
E: ostofriends@gmail.com
T: 07596 748 376
Stevenage Ostomistics
Judy Colston T: 01438 354 018
E: neilcolston@btinternet.com

Isle of Man

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

Isle of Wight

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

Kent

Ashford Stoma Support Group
Carol Hobbs
T: 01303 814 014
Treasurer, David Christian
T: 07970 220 773
Secretary, Maureen Curnow
T: 07989 773 332
Dartford Ostomy Group Support (DOGS)
Tracey or John: T: 07779 155 846
T: 07948 974 350
E: dogs-uk@hotmail.com
Dover Stoma Friends Group Support
Carolyn Fullager T: 01304 821 132
GOGS (Gravesend Ostomy Support Group)
Tracey T: 07779 155 846
Helen T: 07710 780 958
Maidstone Stoma Support Group
Judy/Kirsty T: 01622 224 305
MOGS (Medway Ostomy Group Support)
Tracey T: 07779 155 846
Helen T: 07710 780 958
E: mogs-uk@hotmail.co.uk
Sheppey Ostomy Group Support (SOGS)
Shelley T: 07714 734 194
E: sogs-uk@hotmail.com
SWANS Stoma Support Group Swanley
Heather T: 07711 445 312
E: heather601@virginmedia.com
Thanet Stoma Buddies Support Group
Kathy T: 01843 291 825
Tunbridge Wells Stoma Support Group
Cathy Chitty/Mags Donovan
T: 01892 632 323

Lancashire

Kangaroo Klub, Blackpool Stoma Support Group
Blackpool Teaching Hospital
T: 01253 956 620
E: crc-stomanurses@bfwhospitals.nhs.uk
North Manchester and Bury Stoma Support Group
Julie Meadows (SCN)
T: 0161 720 2815
T: 07774 263 563
Oldham Stoma Support
June Wilde T: 0161 312 5538
Phoenix Bowel Cancer Support Group
Sandra Peet
T: 01772 683 790
W: phoenixgroupbvh.com
E: sandrapeet7@aol.com

Leicestershire

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

Lincolnshire

Grantham Support Group
Bobbie/Rachel T: 01476 464 822

London

Bowel & other Cancer Support Newham
T: 020 8553 5366
Homerton Hospital Bowel & Stoma Support Group
Angela Davy
T: 020 8510 5318
T: 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: 020 8235 4110
Bob (Chairman) T: 020 8428 4242

Norfolk

James Paget Ostomy Support Group
Sandra Hutchings T: 01502 585 955
Kings Lynn Ostomy Friendship Support Group
T: 01553 775 698
T: 01553 674 962
T: 01553 768 271
STARS (STOma And Reconstructive Surgery social support group)
Sylvia Hughes T: 01263 733 448
E: sylvia.ruth.hughes@gmail.com

Northamptonshire

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

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull T: 07714 479 320
Hexham Ostomy Group
Judith T: 07967 927 286
Northumberland Cancer Support
E: members@northumberlandcancersupportgroup.co.uk

Nottinghamshire

North Notts Stoma Support Group
Tore and Nicky Norman T: 01773 715 460
Nottingham QMC Stoma Support Group
Rosemary Brierley T: 0115 982 6691
Nottingham Stoma Support
Jenny or Kate T: 0115 962 7736
Mrs B Heath T: 0115 966 3073

Shropshire

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

Somerset

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

Staffordshire

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

Suffolk

East Suffolk Ostomy Group
Marion Fisher T: 01473 311 204
West Suffolk & District Stoma Group
Jessica Pitt stoma nurse
T: 01638 515 525

Surrey

Epsom and District Stoma Support Group
Lindsay, Trevor or Sheena
T: 01372 735 925
Normandy Colostomy Support Group
Robin Young
E: robin.young11@btinternet.com
T: 01483 417 610
W: normandystomagroup.wordpress.com
Stoma Support Group
Robin Young T: 01428 723 255

Sussex

Brighton & District Support after Stomas (SAS)
Virginia Keefe T: 01273 723 775
Chichester Stoma support Group
The Stoma Care Team
T: 01243 831 527
The Ostomy Friends Group
Jane Quigley T: 01323 417 400 ext 4552
West Sussex Princess Royal Stoma Support
Tina Walker T: 01444 441 881 ext 8318

Tyne and Wear

Gateshead Stoma Patient and Carer Support Group
Stoma Care Nurses T: 0191 445 3152
South Tyneside Hospital and Community Stoma Support Group
Jane Barnes, Amanda Logan:
stoma care nurses
Sunderland Support Group
Michele Downey T: 07704 949 30
E: micheledowney@outlook.com

Warwickshire

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

West Midlands

Birmingham, IA
Michael Jameson
T: 0121 355 2745 / 07842 555 070
W: birmingham.iasupport.org/events
Coventry Stoma Support
Martin T: 07947 385 643

Wiltshire

Swindon IA
W:swindon-ia.org.uk
Wessex Stoma Support Group
Karen Barryman
T: 01980 590 599 or 07799 863 766
E: info@wessex-stoma.co.uk
W: wessex-stoma.co.uk

Worcestershire

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

Yorkshire

Acorn Ostomy Support Group
T: 07580 693 155 (After 6:00pm)
Airedale Stoma Support
Sue Hall T: 01535 646 373
Barnsley Bottoms Up Stoma Support Group
Stoma Nurses T: 01226 432 528
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 and Fiona Holtham
T: 01423 555 786
Leeds Bowel Cancer Support Group
Lynda Castle (Colorectal Nurse Specialist)
T: 0113 206 5535
Scarborough Stoma Support Group
Stoma Care Team T: 01723 342 388
Second Chance Ostomy Yorkshire
Jackie Butterworth
E: Secondchanceostomyyorkshire@gmail.com
T: 07544 882 353
W:secondchance-ostomyyorkshire.org/
The Hull and East Riding Colostomy Support Group
Pete Smith
T: 07989 565 335 or Pete Rennard
T: 07939 518 642 / 01482 793 966
W: hercosg.org.uk

Northern Ireland

County Antrim

Belfast City Hospital Stoma Nurses
Audrey Steele, Karen Boyd, Kirsty Niblock,
Annette Lambert, Emma Dunn
T: 028 9504 5941
Colostomy UK Volunteers Northern Ireland
Chris Wright T: 07720 717 771

County Armagh

Craigavon Area Hospital
Claire Young/ Lynn Berry/ Tanya Garvie
T: 028 3756 1845 (Direct Line)
Daisy Hill Hospital Support Group
Bernie Trainor T: 028 3756 2932 (Direct Line)

County Down

North Down Stoma Support Group
Adrian Ewing T: 07850 741 511
Ulster Hospital
Hazel/Martina T: 028 9055 0498

Londonderry

Causeway Support Group
Mary Kane T: 028 7034 6264

Republic Of Ireland

County Mayo

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

Dublin

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

Scotland

Ayrshire

Ayrshire & Arran Stoma Support Group
Hugh Strathearn T: 07837 464 376
Stoma Care And Recovery (SCAR)
Maggie T: 01294 271 060/ 0781 773 6147
E: maggie13@sky.com or Rhona
T: 01294 557 478

Fife

Fife Ostomy Support Group
Ishbel Barr T: 01592 772 200

Lanarkshire

Glasgow Stoma Support Group
Morag Sinclair T: 0141 779 1322
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
Julian Boswell T: 01554 772 877

Conwy

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

Gwent

Blaenau Gwent Self Help
Celia McKelvie T: 01873 852 672 (after 6pm)
Cwmbran Ostomy Support Group (COSG)
Philippa Lewis T: 01633 791 339 or
07504 713 069

Mid Glamorgan

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

Pembrokeshire

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

Powys

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

Rhondda Cynon Taf

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

Swansea

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

Fundraising

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AR wraparound Ostomy
Hernia Support belt

Tube Ostomy
Hernia Support belt

Mesh Ostomy
Hernia Support belt