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Dear readers



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When I took over as editor last year, I never thought I'd be writing to you all in such unprecedented times.

The coronavirus has cast its shadow over all our lives, from those who have caught and are fighting it, to those who thankfully remain 'free' but are adapting to life in lockdown. As I write this, Boris Johnson is about to start his third day in intensive care; a reminder that this virus, this Sword of Damocles, is no respecter of age, ethnicity, background, culture or faith.

But, as the seriousness of this global pandemic has emerged, so too has that characteristic British resilience in the face of adversity. Galvanised by a common cause, 750,000 people in England alone have volunteered as GoodSAMs. Up and down the country community groups have spontaneously formed to ensure that everyone is looked after. And, the NHS, that institution we seem so obsessed with criticising, has given us all a lesson in humility. With no consideration for their own safety and wellbeing, our healthcare workers (and in this I include those who have returned from retirement and the students – nurses, paramedics etc who have suspended their studies) have responded to the call to arms. This edition of *Tidings* is dedicated to them.

In yesterday's UK government update, the Chancellor spoke about charities and the role they are playing in supporting people. He said: "it is a terrible virus, but we are not facing it alone". This is a message that I want to echo to the readers of *Tidings*. **Colostomy UK** is still here and ready to help and support you in any way we can. On page 6 Libby Herbert, our general manager, and Mandi Laing, chairperson of our board of trustees, explain in more detail how we are continuing to support ostomates. This is followed by a message from our president Ian Daniels FRCS. On page 9 Emma Howell, our volunteers' manager, gives an update on our volunteers and how they are still working as hard as ever! She shares too, how one of the team is keeping herself occupied during the lockdown. On page 15, you can also read about one of our volunteers who succumbed to the virus last month but is now home from hospital and well on the road to recovery.

I know from the messages I receive what a vital role *Tidings* has in supporting people. For many, just reading about the lives of other ostomates helps to relieve feelings of isolation. With things as they are now, we've done all we can to produce a bumper edition for you this time round. Inside you will find most of the regular features. Despite the pressure on healthcare professionals we even have Dear nurse, with Karen Totty taking a look at stoma stenosis. Our real lives stories (of which there are five) are very diverse covering everything from preparing for your wedding as an ostomate, to the experiences of stoma surgery two centuries ago. The importance of art and the importance of arts and crafts is a recurring theme too. This is of course pertinent, as we all try to find ways to keep active under the current restrictions. In her article, Gillian Cowell (our newest member of the editorial board) explores the benefits of arts and crafts to mental wellbeing, while Giovanni focuses on activities you can do at home (physical and mental) in his regular update on our Active Ostomates project. To round things off, we have a contribution from an ostomate in Canada, who talks about her work with children who have stomas and their families.

I'm going to finish by sending my best wishes to all readers. Stay safe and don't forget, we are in this together. Our stoma helpline is open 24/7. If you are lonely, it's quite ok just to call for a chat! The immediate future remains uncertain, but my hope is that things will have returned to some semblance of normality by the time I write to you next!



Richard

Richard Biddle
Editor,
Writer & Researcher



RAW STORIES LESS SORENESS

Chris described having stoma surgery as a big change and experienced very irritated skin to begin with. Thankfully she found ways to improve the skin around her stoma and now it looks just like it does on the rest of her body.

Head to www.clinimed.co.uk/rawstories to learn more from Chris about why managing stoma skin health is so important to her.

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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.

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24 hours a day and completely free.

Adminline for:

Information packs, ID cards, RADAR keys, travel certificates and literature.

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If we're not in, just leave a message.

info@ColostomyUK.org

To request (or cancel) your quarterly copy of *Tidings*

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



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Donating to Colostomy UK

An annual donation of £20 (or whatever you can afford) allows us to produce *Tidings* and to continue our vital work, supporting, and empowering ostomates – see page 47 for donation form.

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

Colostomy UK: news

A message from:



Libby Herbert
General Manager



Mandi Laing
Chairperson,
Board of Trustees

Dear readers

It is fair to say that the last few months have been challenging for everyone and with it still unclear when we will return to normality, we thought it was important to send a message of solidarity to our readers. We also wanted to use this opportunity to let you know what's happening at Colostomy UK and, in particular, how we are continuing to support ostomates and their families and friends, as we stand together in these troubling times.

Towards the end of March, we took the decision to temporarily close our offices in Reading. As you will readily appreciate, guarding the health of our people is always paramount. The office team are all still working, but remotely from home (above centre). This took a little while for everyone to get used to but, thankfully, as you will see from the pictures, we are all now settled! We still hold our weekly team meeting and are keeping everything flowing smoothly through regular e-mails, phone calls and 'electronic' catch-ups. For some, such as our IT-reluctant editor of *Tidings*, this has meant getting to grips with video conferencing! Morale in the team remains as good as ever, helped by the fact that we still find the time to share a laugh and a joke; something that is perhaps more important now, than ever before.

At the moment, there are of course no open days or face-to-face support group meetings for us to attend. Additionally, we have suspended all hospital visiting for the time being. However, aside from this, we are pleased to confirm that our other services are operating more or less normally. We hope this will continue for the foreseeable future, but our ability to do so is dependent on the generosity of our supporters and the donations they make.

Thanks to our volunteers, our 24-hour Stoma Helpline continues uninterrupted. In addition, we have doubled the number of telephone lines (between 09:00 and 17:00), in anticipation of higher demand over the coming months. We are also looking at how we might extend our service (you can read more on page 9). By the time you receive this edition of *Tidings*, we will have also started to offer 'live chat' on our Website during office hours. This will allow visitors to the site to communicate (by text) with a member of the office team. We hope this will prove popular, especially with ostomates who prefer to 'type' rather than 'speak' or

perhaps want to ask questions anonymously. We have also added a page to our website dealing specifically with the coronavirus and how it might impact people with stomas*. Our private Facebook support group is continuing as normal (see page 50 for information on how to join). All the literature we produce is free to download on our website. If you would like any titles in hardcopy, then please e-mail your request to: info@ColostomyUK.org and we will send them to you as soon as our office re-opens. *Tidings* is also being produced. Indeed, by the time you read this, work will have already started on the autumn edition.

As you are doubtless aware, we also operate an 'admin' telephone line, where you can call to request copies of our literature, order things like travel certificates and make non-urgent enquiries. Until further notice, we request that you e-mail us at: info@ColostomyUK.org rather than calling this line. This makes it easier to deal with your enquiries. We are also unable to process requests for RADAR keys and ID cards at the moment. It is fine to send these to us, but they won't be processed until our offices re-open. As usual, urgent calls should be directed to our Stoma Helpline: **0800 328 4257**.

We appreciate that there is a lot of information to take in here! But, our central message is a simple one: We at Colostomy UK are here, as we always are, ready to help and support you in any way we can. If you have a stoma-related question or need some experience-based advice or are just lonely and need to speak to someone, please don't hesitate to get in touch.

Yours sincerely
Libby & Mandi



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emotional support, experience based
advice and guidance from a volunteer.

0800 328 4257

24 hours a day and completely free.

info@colostomyuk.org Registered Charity Number: 1113471



***Just as we went to press, we posted an update on obtaining prescriptions for stoma supplies.** We know that this is a concern for many ostomates. You can read the full update by visiting our coronavirus webpage (<http://www.colostomyuk.org/covid19/>) and clicking on 'useful advice'. In summary: product manufacturers have reassured us, the British Healthcare Trades Association, The Urostomy Association and The Ileostomy and Internal Pouch Association, that there is no need to stockpile supplies and that ostomates should order in the normal way. If people continue to do this, then the manufacturers do not anticipate there being any problems with supply.

Covid-19, Colostomy UK and counting the days

What a challenging start to 2020 we are having. Sadly this “very very nasty cough going around” is causing untold misery and loss of loved ones for many families across the UK and around the world. As a healthcare professional I have witnessed amazing courage and selflessness from colleagues across the NHS and in social care. We have had to empty hospitals, create extended ITUs by converting operating theatres or even building new wards, we’re being retrained or relearning stuff we thought we left behind at Med School and prepared ourselves for the influx of humanity. As the social distancing is impacting and as yet we haven’t been overwhelmed, we’re now left wondering where all the people we would normally see are? Whilst we have introduced new “phone clinics” some things can’t be replaced such as examining someone – I certainly don’t want to receive mobile phone pics of all sorts of bits of anatomy – bottom, poo and stoma selfies are not to be encouraged in my e-mail inbox!!

It’s through these challenging times, the support of charities such as ours has proved invaluable, as stoma care departments have lost staff redeployed into ITU etc. meaning that the wonderful staff we have left, have been working harder, also developing new ways to work but still having direct patient contact and being there to help.

So what happens next? In the medical world we’re all asking the same questions: When will we come out of lockdown? When can we start “normal services again” although the way we deliver “normal services” will have to change and how? Will Covid-19 always be there? How can we keep people safe in hospital – both patients and staff? When can Team Colostomy UK (#UpThePurps) play rugby again (very important for me and the team)???

As a charity we have also had to change. Whilst still led by the wonderful Libby, the team are working remotely from home, meetings are now in the virtual electronic world linked in from the front room, bedroom, kitchen or bathroom(!) and all external events we run/support are gone (for now), but the helpline remains and the website and tweets are still getting our messages out. We’re still there for you.

Many of you are “locked down” in your homes, but how important has it become to just get outside and go for a walk – even though I still have to go to work (it’s now the safest on the road to cycle ever!!!) we all seem to rediscovered walking and the air seems so much cleaner. I can’t imagine how difficult it must be home schooling, wondering about jobs, paying the bills, missing parents, friends, etc, but **Colostomy UK** are still here, remember it’s important to talk (these are challenging times mentally as well as physically), clever people will find a way to beat the “nasty cough” and hopefully soon we can all get back to living life, playing rugby, going swimming, doing chair yoga and being active ostomates again!

PS: Thanks for the claps on a Thursday – the first time I heard it was really touching, but also clap for all those keeping our world going, and not least the Team at **Colostomy UK HQ**.

**Ian Daniels FRCS
Consultant Colorectal & General Surgeon**



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Colostomy UK: volunteers



Emma Howell
Volunteers Manager
E: Emma.Howell@ColostomyUK.org

As I am sure you can imagine, the coronavirus pandemic has, and continues to have, an impact on our volunteers. Just like everyone else they have had to adapt to all that comes with social distancing and, in some cases, self-isolation. Unfortunately, one of our volunteers also succumbed to the virus back in March and spent some time in hospital as a result (you can read about her experience on page 15).

The needs of ostomates continue however, regardless of the virus. In fact, for some, their needs may even increase, perhaps because they are living alone and have no-one around to share the daily ups and downs of life. Similarly, I am sure that some will be struggling, as the current rules on social distancing have led to the cancellation of support group meetings. All in all, it's a very challenging time.

A clap for our volunteers!

In the last edition of *Tidings* I ran through the many things our team of volunteers do to support ostomates. If you remember, this included everything from helping in our office with general admin, through to attending open days on our behalf and taking calls on our 24-hour stoma helpline. This time round, my plan was to tell you all about the training our volunteers receive before they go 'live' but, as they say, the best laid plans...

So instead, I'm going to take the opportunity to explain how, thanks to our volunteers, **Colostomy UK** continues to be open for business and even has plans to extend some aspects of the support we offer.

At the moment, there are no open days for our volunteers to attend. Hospital visiting, fundraising and local campaigning are off the agenda too, but our 24-hour stoma helpline continues to operate as usual. This is only possible because of our volunteers. Outside of office hours, the helpline is run remotely. This means that when you call it and speak to a volunteer, they will actually be taking the call in their own home. Hence, we can continue to offer this core service, without putting any of our volunteers at risk.

Almost as soon as the seriousness of the coronavirus became clear, we started to receive calls from anxious ostomates. In order to ensure that our volunteers were (and are) equipped to respond to callers' concerns, we have been regularly updating them with the latest information on Covid-19. We have also been sharing some the key questions asked by callers to the helpline.

As I write this, we are considering how we might extend further the support we give through the helpline. This might include weekly 'check-in and chat' calls with our volunteers for ostomates that are perhaps lonely or generally struggling with the current restrictions. We are also looking at whether there are ways in which we might be able to link callers to support available in their local community. Although we are still at the planning stages (check our website

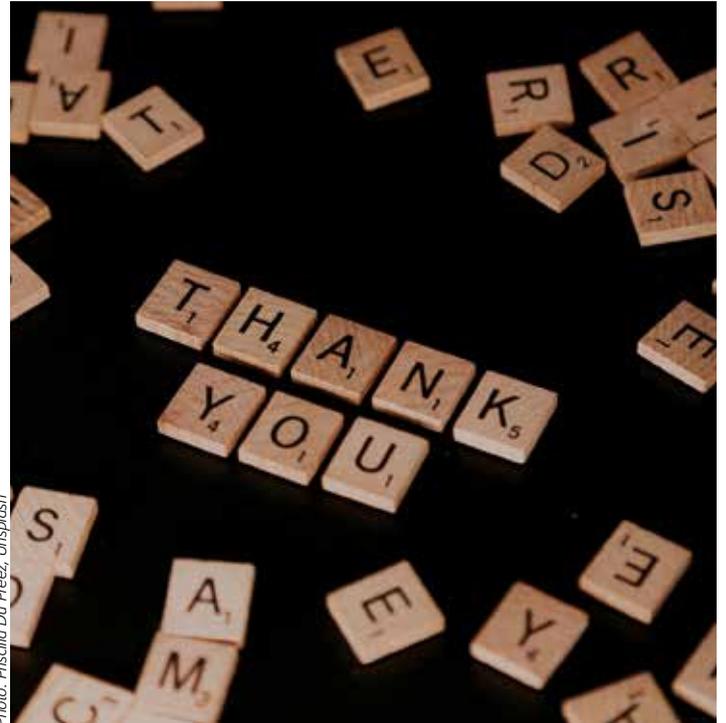


Photo: Priscilla Du Preez, Unsplash

for developments) one thing we certainly don't lack, is skilled and experienced volunteers who, day after day and week after week, dedicate their time to helping fellow ostomates!

If you are worried or perhaps just want to speak to a friendly voice and spend some time with someone who will listen, then I urge you to pick up the phone. **Colostomy UK's** volunteers are ready!

And finally...

I thought I would finish by sharing what Bobby Minshall, one of our long-serving helpline volunteers has been doing to keep herself occupied while in lockdown and in-between calls:

*Hello my name is Bobbie, I am 63 and I am one of the volunteers for the **Colostomy UK** stoma helpline. Being a greedy person I have two stomas, a urostomy since 1991 and officially a transverse colostomy, since 2009, which behaves like a high output ileostomy due to having a mere 1.2m of small bowel. I also have lymphoedema in my left leg. However, this does not stop me leading an active life with golf, walking, and helping to look after my 'grandmonsters'.*

So what do you do if you cannot go out as normal? I usually play golf four to six times a week in the warmer weather and three to four times in the winter. I am accustomed to being outside doing things and now suddenly the world has gone a little bit crazy and everyone is being advised to stay at home. We are allowed to go for a walk or run, but not on the golf course unfortunately. My husband can go out for a run but I am not capable of that. Hence, as we are permitted a walk, we have been walking to the nearest village and back. This is around five miles but

CONTINUED ON PAGE 10, COLUMN 1

CONTINUED FROM PAGE 9, COLUMN 2

as we live in the wilds of north Northumberland, close to Scotland, we rarely see anyone else along the way.

I am a crafter as well and I have already made 100 Christmas cards ready for later on this year. Then I remembered a friend gave me a kit for my birthday. It is comprised of numerous coloured beads 2mm in size which are raised on one side and flat on the bottom and a sticky picture which the beads are supposed to be stuck to following the colour guide. When I got this I thought I would never have the time to do it and it looked frightfully fiddly, and I am not a fiddly person! But circumstances suddenly meant we were all housebound. So I thought this would be the ideal time to do this kit. The tool which came with the kit really didn't work so I found some tweezers to pick up the beads which worked much better. I definitely needed good light, so it was a daytime job.

Five days later it was finally finished with a big sigh of relief. Mind you I have never seen a cat with these strange colours but it's done. So now what? Back to card making, cross stitch and lace making I suppose, but that's another story...'

Bobby

I hope that by the next edition of *Tidings* life will be returning to 'normal' and I can give you an update on the volunteer training that we regrettably had to postpone. In the meantime, if you would like to find out more about any aspect of being a **Colostomy UK** volunteer, then please do not hesitate to drop me an e-mail: **Emma.Howell@ColostomyUK.org** ■



One of Bobby's 'fiddly' fish

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Here you can see a surgeon letting blood
Interior of a surgery with two operators.
Courtesy: Wellcome Collection. Attribution 4.0 International (CC BY 4.0)

Mr Norman also agreed

in thinking that an artificial anus offered the only resource of prolonging her life:
A look at stoma surgery in early nineteenth-century England
Richard Biddle

What follows unashamedly taps into the morbid curiosity we all have about surgery in the past, or 'blood and guts' as the late Roy Porter so eloquently put it. In previous editions of *Tidings* we have published pictures of stoma bags from the 1960s. You know the ones, those impractical rubber affairs with a belt to hold them in place. Well this article rolls the clock back even further, over two centuries in fact, to talk about early stoma surgery. To do this, I'm going to be drawing on some notes left by a surgeon¹ practising in England in the 1820s and reconstructing from these the journey one of his patients took, revealing how serious illness led them to submit to the knife.² But before probing further (my last surgical pun I promise), a warning: this article is best read either hours before dinner, or hours after, when you've had plenty of time to digest what you've eaten...

Prior to introducing our surgeon and his stoma patient, I want to say a little about early understandings of the body; the reasons for which will become clear later on. Up until the early nineteenth century medicine worked within what historians call a 'Galenic' framework. This saw the body in terms of the four 'humours' (blood, phlegm, yellow bile and black bile). Everyone had these and it was believed that when they were in balance a person was healthy. Conversely, if they went out of balance, illness followed. The causes of imbalance (or illness) were thought to be varied, including everything from breathing

bad air, to eating the wrong things, to doing too much or not enough exercise, to reading too many books or watching plays that got you over excited. When somebody became ill, their physician would try to cure them by restoring their 'balance'. This is why bloodletting was so popular, as it was believed that letting blood was an efficient way to get rid of excess or bad humours. For the same reasons, medications that made patients vomit, sweat or go to the toilet were prescribed; these bodily functions being considered 'nature's' way of maintaining balance.

The above was significant for surgery. If you believe that the causes of illness are the result of an imbalance in bodily fluids, then you have no basis for surgery: why would you think you could cure someone by opening up their body? Instead, surgeons (and barber-surgeons) spent most of their time bleeding patients, treating things like sores and stitching up wounds. The latter occasionally involved operating on the bowel (usually when it was exposed through injury). Hippocrates (460–377 BC) referred to such wounds as 'deadly'. Writing several centuries later, Celsus (53 BC – 7 AD) recorded that if the large intestine was damaged from a stab wound it could be sutured and would occasionally heal, which he thought was preferable to 'certain despair'.³ Surgery in the modern sense, didn't start to develop until after the French Revolution (1789–99) and the success this had in toppling the established order (including Galenic medicine). Importantly,

it allowed doctors to think without God. In the Paris hospitals this led to the discovery (through dissection) that disease was often localised and would attack specific organs. Hence the surgeon with which this article is concerned was a pioneer, being amongst the first to attempt to cure by delving into the dark recesses of a patient's body.

Our surgeon is Mr Pring, who was a member of the Royal College of Surgeons in London. In 1820 he operated on Mrs White a 64-year old widow, who he described as never having 'bourne children' and 'rather of a full habit, with a florid complexion'. In the summer of 1819 Mrs White, who had been healthy all her life, started to be troubled by 'acute pains in her abdomen' and her stools began to contain blood. Thinking that her disease was 'dysenteric' Pring began treating her with, amongst other things, opium and mercury. The latter he had to discontinue, when her teeth became loose, her tongue sore and an ulcer formed on her cheek. This was something of a disappointment for Pring, as under this regime he maintained her symptoms had improved. Within a few weeks Mrs White was discharged, feeling much better.

By the autumn however, she was unwell again, alternating between terrible constipation and abdominal pains, to explosive diarrhoea. In March 1820 she returned to Mr Pring, after she felt an obstruction in her lower bowels. She explained to him that 'everything seemed to stop in one place'. Pring immediately

started tests. These included using rectum bougies (probes) of ever increasing sizes, from which he established that none would go further than seven inches. He then used a 'large-sized urethra-bougie' and found this stopped at the same place. While conducting his tests, he initially tried to relieve Mrs White's symptoms through the use of castor oil and Epsom salts. These worked for a while but in July, he recorded that the obstruction appeared to be 'complete' and that he had exhausted all 'medical resources' in 'fruitless attempts' to evacuate her bowels. Between March and July, Mrs White had endured salts, Senna, aloes, colocynth, jalap, scammony, gamboge, elaterium and calomel, all given in the 'largest doses'. She had been bled on a number of occasions (revealing that Pring still put store in aspects of Galenic medicine). She had also suffered 'injections of every sort' which included, towards the end, Pring attempting to use a flexible catheter to get past the obstruction so that 'clysters' (an enema) 'might be thrown into the bowels above the seat of it [the obstruction]'.



Case of surgical instruments from around the time that Dr Pring operated on Mrs White
A case of surgical instruments, by Down brothers
Courtesy: Wellcome Collection. Attribution 4.0 International (CC BY 4.0)

At this point, Mr Pring consulted fellow surgeons Mr Norman and Mr Skinner, one of whom had treated a patient with similar problems. In this particular case the patient had died. Fearing that Mrs White was rapidly moving in this direction too, they decided that the only answer and 'chance for her life' was to make an 'artificial anus' (a colostomy or ileostomy). The situation was explained to Mrs White, who consented to the surgery. This was a brave decision, given that we are talking about a time some decades before the discovery of anaesthesia. Perhaps she was so unwell and so battered and bruised from months of treatment, that she was beyond the point of caring and simply wanted the ordeal to end? What's more, neither of the men had ever performed such an operation, although in his notes Pring mentions having seen a successful case detailed in a medical journal. He also

references the French surgeon Duret and the colostomy surgery he performed on a baby in 1793. As a side point, this was the exact same case mentioned by Ambra Bertinara in her recent irrigation article (*Tidings* Winter 2019).

Mr Pring and Mr Skinner performed the operation together. In his notes Pring details everything from the first incision, through to laying bare the peritoneum and making an incision in this membrane, at which point Mrs White became 'greatly agitated' with her diaphragm and abdominal muscles 'thrown into violent action'. He describes too how on cutting into the 'gut' the contents of the bowels 'were immediately expelled with great force to a considerable distance', after which he was able to complete the procedure. It is also clear from Mr Pring's notes, the great care and concern he took over his patient. This was evident before, during and after the procedure.

Mrs White initially recovered well and within a day was having gruel and beef-tea, as well as medicines to relieve constipation. However her ordeal wasn't over as by day three her wound had become inflamed and the stitching started to break down. Over the next two weeks she became very ill and was left with a large 'ill-conditioned, open wound and the sloughing of the cellular membrane and fascia under the skin was so extensive that a probe would scarcely reach the termination of it in any direction'. Mr Pring feared she would die, but Mrs White had other ideas. Five weeks post-op her wound started to heal and this healing

increased rapidly as her general health improved. In his notes, Mr Pring graciously attributes this to her having an 'excellent nurse' (the first stoma care nurse!) 'whose constant and indefatigable care in cleaning the wound and removing dirty clothes' had ensured that 'great additional mischief' was prevented. Five months down the line, Mr Pring was pleased to record that the object of the operation had been 'completely obtained'. Mrs White had regained her 'florid complexion', her general health was good, her pulse was a steady 70, she was 'well disposed to make the most of her food' and had recovered her flesh 'to a great degree'. She had also seen no return of her 'dysenteric symptoms'. She was, however, experiencing issues that will ring a bell with many readers. These included occasional rectal discharge and a prolapsed stoma. The latter was managed by her wearing a truss containing a circular spring, which was kept in place 'by means of straps'. Sadly for us, Pring never makes it clear what was used to collect waste from Mrs White's stoma. His notes mention a 'large pouch' being used in the immediate post-op weeks which constantly leaked, causing sore skin – but nothing about arrangements afterwards. Having spent the last 15 years researching and writing history I can tell you that's par for the course. There is always some vital piece of the jigsaw missing. The important thing though, is that thanks to courageous men like Mr Pring and Mr Skinner and brave people like Mrs White, patients of today receive life-saving stoma surgery. ■

¹The modern use of the word 'surgeon' came later, once surgery had developed as a specialism. In the period with which we are concerned a surgeon was more akin to a general practitioner.

²Pring, D (1821) *History of a Case of the Successful Formation of an Artificial Anus in an Adult* The London Medical and Physical Journal, 263, 1-8.

³Richardson, RG (1973), *The Abominable Stoma: A Historical Survey of the Artificial Anus* (Abbott, Kent).



By 1900 surgery was beginning to look more like we are used to. This image is of the Old Operating Theatre, Charing Cross Hospital
Charing Cross Hospital: Stanley Boyd in the old operating theatre. Photograph, 1900
Courtesy: Wellcome Collection. Attribution 4.0 International (CC BY 4.0)

Stay Connected



At Medilink®, we were aware that there would be many vulnerable people in our society who had been asked to self-isolate for their own protection and the protection of others during the coronavirus crisis. A large number of people living with a stoma would be included in this category, and many of these people could be living alone without anyone to keep them company. So the Medilink Stay Connected support service was set up as our way of trying to lessen the feeling of loneliness.

By simply calling or registering on our website, those who were feeling isolated could easily request a call-back from one of our Customer Care Team. This team was made up of dedicated and experienced volunteers from within our wider workforce – many of whom were unable to do their usual jobs during this period. Each day our team called all those who had registered, and chatted to them about a wide range of topics from the weather to gardening, and even what was on the menu that week!

We received some fabulous feedback from those who received calls, and were delighted to know that we had helped to lift the spirits of those feeling a little lonely:



Lovely to talk to someone
when you're feeling down and just have a nice chat.

*It was **so nice to talk to someone and have a chat.** I live alone and only get out twice a week to get a bit of shopping. I wasn't feeling too good that day, **so it really brightened my day.***

*I would like to **thank the people whose idea this service was,** and those who have put it into action!*

*I was **very grateful to hear a friendly voice** and to have someone to share things with.*

Appreciate the chat
to break the boredom!



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Take nothing for granted and don't be afraid to care: reflections on surviving COVID-19

I am a wife, mother of three adult daughters, a grandmother, retired primary special needs teacher and a dual ostomate. I am in my late 50s and live with my husband whom I have been with for 40+ years. We live in Surrey in a fully adapted bungalow with our two youngest daughters: aged 26 and 29.

In 2002, I sadly sustained a traumatic spinal cord injury (injured by a pupil in my class), which left me with serious nerve damage to the lower spine and organs. In addition, my mobility was affected, and I was left needing to use walking aids when indoors and a wheelchair/scooter when out and about. I have two stomas, which were fashioned in 2008: a colostomy and a urostomy (ileal conduit – no bladder). The stomas were needed primarily because the nerve damage to my spinal cord caused incontinence, but also because I contracted C-Diff, E-Coli and sepsis, which led to severe dysfunction of both my bladder and bowel. Over the years I have needed further surgery and treatment due to cancer (a tumour found in the bowel tract), bowel stenosis and fistula disease of the ileal conduit. I have also had both abdominal and parastomal hernias repairs.

Despite and in spite of my condition, 'life is good for me'. For the past three years I have worked for **Colostomy UK** as a volunteer, which I find extremely rewarding. Away from **Colostomy UK**, I am a patient advocate for dual ostomates and, in conjunction with my local hospital and specialist team who look after me at University College London Hospitals, I produce essential literature/advice for those living with a stoma (or two!). In addition, I undertake secretarial duties for the Patient Participation Group for my local doctor's surgery.

I enjoy going to concerts with my husband; seeing and listening to our favourite funk,

jazz-funk and R&B artists perform, as well as going to the cinema with my children too. Nothing beats a good Marvel or Star Wars epic! I travel when I can and have been fortunate enough to visit both mine and my husband's place of birth, Mauritius and Jamaica respectively. The best thing for me is spending time with my family, especially being with and looking after my amazing granddaughter.

For me, 'life is for living' and nothing stops me doing this. In fact, living life to the full is something of a family mantra. I know people often say things like this, but never has the value of life and the value of sharing that life with my family and friends ever been so clear to me as in the last month or so.

Early in March I began having hot and cold sweats and chills. Within a few days this progressed to a persistent, annoying dry cough. By day four the cough continued to progress and this was then accompanied by acute pain in my chest with the inability, for me, to actually catch my breath. I phoned my GP who, knowing my medical history and hearing my symptoms, advised that I immediately contact NHS 111. My daughter then spoke to a triage nurse on the phone and as my symptoms were being documented, they became very concerned that I could not even talk without coughing and wheezing with pain. An ambulance was discharged to my home and after the paramedics had carried out their assessment, I was blue-lighted to hospital.

After four days in hospital on a ventilator and given a nebuliser, oxygen, adrenaline and surprisingly penicillin, I thankfully was able to come home; albeit on the strict instructions (of the Hospital's Chief Consultant) that I rest and follow the medical team's guidance. In addition, all my family had to isolate for 14+ days. I was

fortunate enough, on discharge, to have been given a nebuliser and inhaler to use at home, which were a necessity to helping my breathing normalise.

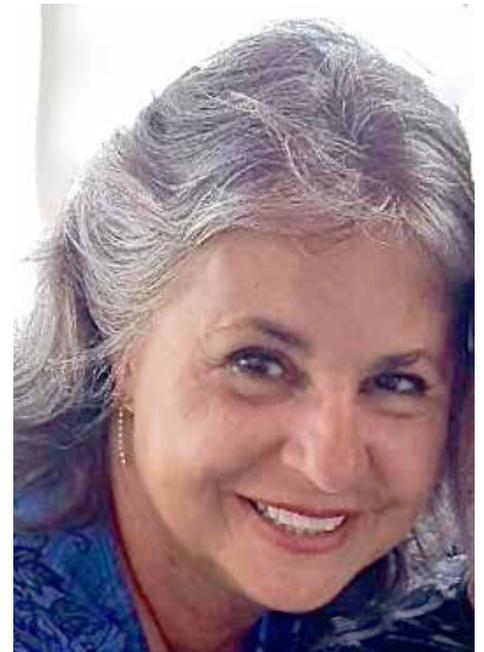
I am now well on the way to recovery. I think it's also important to point out that not everyone ends up in hospital like I did. In fact, it seems that milder symptoms are more common, but just contracting coronavirus is scary. I'm sure that I won't be the only person to say that it has helped me to put life into perspective. As I listen to the news each day and hear of the virus' spread and the suffering caused in its wake, I feel that I am one of the lucky ones. It has made me think about those I hold dear, those I love and those I care for and realise just how precious they all are and how fragile life is. We really need to start thinking of others, because all too quickly it can disappear. What we take for granted, such as the ability to breathe without pain and without the need for machines, can so easily be denied us by this disease. It is hard to think that something so innocuous as a virus can take that away in a millisecond.

I'm going to say it again, but I consider myself to be very lucky. I have been through many tribulations in my life, the virus being the latest and I can say that to breathe and take in breath without pain, with the ability to lift my head and see my family and enjoy the simplest things, such as a meal, cannot be measured. And yes! We can't hug each other at the moment, we can't give each other a kiss. But, we can do this in so many other ways...a word, a prose, a song. We can just pick up the phone, just text, just app! Because, through this we will all turn out, I'm sure, a little more caring, a little more compassionate and a little more resilient too. ■

Name withheld

The Littlest Ones

Jo-Ann L Tremblay
Ostomate
Author



Ed's note: Regular readers will know that in our spring 2020 edition we looked at children with stomas and the challenges that they and their parents face. The piece below (the first of two instalments) helps to keep the spotlight on this important, but all too often neglected, topic. The author is a Canadian ostomate, something you will pick up from the way she writes and the terms she uses. What you will also see, is that while the language may differ, the needs of ostomates and their families across the Atlantic are very much the same as our own.

I am an ostomate and Percy is my stoma. From the moment in 2011 when Percy was created, I began my journey towards ostomy awareness and advocacy. As part of this journey, I have the honour of being a member of the Ostomy Canada Society, Medical Advisory Committee, serving as their resident 'Ostomy Lifestyle Expert'. I have the responsibility of receiving and responding to a wide range of ostomy questions, via the ostomycanada.ca website: 'Ask the Ostomy Lifestyle Expert'.



Some of the questions I receive are from parents of children with ostomies. Unfortunately, there are very few resources available such as: paediatric ostomy support groups, children's books, toys, videos, etc. This is challenging for the children and their families. As part of my ostomy awareness and advocacy commitment, I have teamed up with several paediatric ostomy families, our goal is to shine a light on paediatric ostomy.

Having children brings with it the joys, beauty, trials and miracles of life. All children are perfectly unique, and so, some children have an ostomy. Whether a stoma is formed as a baby or as an older child, there are many medical reasons why a stoma will be recommended. These can be due to an injury, birth defect or underlying disease. The Littlest Ones features Mallory and her family.

'Miracle Mallory' of the Mayo Clinic is now four-years old. Mallory and her family's journey started on the second day of her life. She was born with 15 congenital defects and her bladder was open to the outside, a condition known as cloacal exstrophy¹. This is an uncommon birth defect occurring in only one in every 400,000 live births in Canada. Mallory has an ileostomy.

Her mom states: "We believe her ostomy is permanent at this time, but science is amazing. Time will tell. "At first Mallory had a colostomy, but it failed to work. After ten days of no poop, it had to be modified to an ileostomy. We lived in the hospital for the first 104 days of life. We were in the neonatal intensive care (NICU) for the first 84 days. Support in the NICU was high. Meeting with ostomy nurses is blessed time to learn as much as possible. While Mallory was an inpatient, I did as many bag changes as possible. We have the support of 12 specialists, who are available 24/7. We have direct contact with a wound, ostomy and continence (WOC) nurse (email and phone)²."

As with most adult ostomates, paediatric ostomates and their families rely on peer support. This can be involvement with an ostomy support group, ostomy associations or societies, and through social media.



"Promise me you'll always remember you're braver than you believe, stronger than you seem, smarter than you think, and loved more than you know." – Christopher Robin

"We are a part of a Facebook group filled with other families and patients, most of whom have ostomies. It's a great place to share information and exchange ideas for Mallory's care," says Mallory's mother.

"Mallory has issues trusting others to care for her ostomy. She is 100% comfortable with Mom and Dad, but with all others, she feels they are just not quite good enough. We change the bag daily to prevent leaks at daycare. We have trained our teams excessively and use Facebook video chat to help resolve on site issues. We rarely ask for overnight care because our loved ones are just not comfortable with providing around the clock care in case something goes wrong."

"We talk about Mallory's body a lot. It is important to normalize her thoughts, ideas and images of her body. We are able to tap into resources with our online Facebook group, she can see others just like her. We also talk about how and why things are this way. We have taught her to love her ostomy because without it she would most likely not be alive," admits Mallory's mom.

"The talks are more often and more in-depth as she becomes more and more wise. My biggest lesson learned is personal. I had to learn how to remove the emotion from the conversation. If she is not making it emotional, then I do not make it emotional. I had to realize it was just a question, not a tragedy. For example, why doesn't my brother have a bag? I used to sob and sob before I answered the question. Now...I simply answer the questions. He doesn't need one. When he was born, his tummy worked fine. When you were born you needed a little help, so your doctor gave you a bag. This has given her the freedom to ask questions vs upset mom. We are in a much better place now. I believe one of the struggles that we will encounter is body image. We have some years to prepare."

Paediatric ostomy parents are creative and innovative. The following are some skills and tips Mallory's parents wanted to share:

- ❖ Mallory's parents built a change table for her. As a four-year old, she outgrew the standard baby size.
- ❖ When it seems like every single bag is leaking, it's not you. Whenever we hit a big growth spurt, bags did not stick. Mallory's parents, who feel they walked into this blind, wish they could go into a manufacturers lab and play with products. "We wish we could go in and learn what products exist, get a few samples, and increase our basic knowledge. We would love to give them feedback on what we notice and see in the products. It would be an amazing resource."
- ❖ Never blame your child for issues with the bag. It's not their fault and it is just poop. Mallory articulates non-stress mannerisms when things go wrong: "It's just poop, right mom?" "I've helped her understand it is not the end of the

world." Give your child a vocabulary and narrative to talk about the ostomy with others. All children are honest, they will just plain ask.

- ❖ Normalize...normalize...normalize, do it as much as possible. "I even wear wafers and bags just stuck to my skin, (when Mallory asks me to be like her today)."
- ❖ Keep an extra supply of equipment on hand. An emergency ostomy supply will give you a ton of relief.
- ❖ Use technology like YouTube, to educate caregivers.

No matter our age, an ostomy saved our lives. We have another chance at life. We know how important it is to live life to the fullest. Our paediatric ostomy families have important messages they want to pass on:

"Ostomy bags are a tool to help you live life. They are not a death sentence or area of shame. Don't let it slow you down. The products are engineered to withstand life in action. The ostomy will not sideline you. Only you can sideline yourself. I have watched Mallory straight up belly flop onto the hard floor with a bag full of poop, and we are all good, over and over and over. Live life!"

"It's just poop. We have stressed this over and over with Mallory's caretakers and it helps them so much. No matter what goes wrong, in the end it is just poop. It is not an emergency. If you can figure out a way to catch poop, you win. This has given her caretakers the ability to take a more relaxed approach, and be creative when needed," explains Mallory's mom.

Mallory's family are working together to shape Mallory's sparkling spirit. As parents they embrace their role as medical parents. They are often asked, how do you do it? "The answer is simple, it's just love. We just love her the very best we can. If that means making a doctor's office a fun adventure zone or a game of 'I SPY,' we do it. If that means holding her down so we can get access to her veins for an IV, we do it. Any parent could be a medical mom/dad because it's just love."

The littlest ones and their families are extraordinary. Sometimes in life, moving forward takes bravery. Ostomates of all ages can attest to that.

Paediatric ostomates are the future and they march steadily towards it. They inspire us by their true-life stories. By their journey. By their messages. As they enrich the lives of their families, they also enrich ours. ■

Ed's note: The next instalment will appear in the autumn 2020 edition of *Tidings*. This looks at Delia and her family and the challenges that come with being a teenage ostomate.

¹The NHS uses the terms bladder exstrophy and epispadias.

²In Canada WOC nurses serve in a variety of roles, including educator, consultant, researcher and administrator.



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Bride with a stoma

Rachel Carthy



As any bride-to-be will tell you, making sure you look great and feel good on your wedding day is a bit of a concern. It certainly was for me as the occasion drew ever closer. Now, when I think back, all I can do is smile! Who would know from the wedding photos, that just a few years before I had had a pan-proctocolectomy and permanent ileostomy formed? I wanted to share my story and how I prepared for my wedding in the winter of 2019, in the hope that it might inspire or give confidence to other women, perhaps in a similar situation, who are worrying about their big day.

I was diagnosed with Crohn's disease in 2002. This came after just over a year of stomach pains, rushing to the loo and blood in my stools. I went on to have many different procedures in the years that followed. These were mostly exploratory in order to check-up on my Crohn's. I had plenty of flare-ups along the way, but by managing these through courses of medication, I was able to get through sixth form, university and start my career. For long periods of time I took Loperamide to slow down bowel movements and Azathioprine to control my symptoms. If I had a flare-up, I would use Pentasa Mesalazine suppositories or Prednisolone steroids (sometimes orally and sometimes intravenously, if I was admitted to hospital).

During these years, I considered myself fairly lucky. I knew that some cases of Crohn's required surgery and yet I'd enjoyed fairly good health up to this point, being able to complete my studies and start full time work. However this all changed at the beginning of 2015, when I became very poorly. I had a flare-up, but I knew something was different this time. My symptoms were far worse than anything I had experienced before and the medications I usually took just weren't 'kicking it into touch'. After a couple of short hospital stays to go on IV steroids, I went to an emergency clinic. From here, I was admitted to hospital, adamant that I would stay long enough this time for them to really get to bottom of things (no pun intended). My employer was very accommodating; I told them I would probably only be in for a week...fast forward two weeks and I was still in hospital on a low residue diet and trying biological drugs via IV for the first time. I began with Infliximab, but I reacted badly to this and so a second dose wasn't possible. With no improvement and the results from tests showing lots of ulcers, inflammation and swelling in my large bowel (colon) which, in the words of my consultant, was 'on fire' the time had come to consider surgery and, potentially, a pan-proctocolectomy (removal of the large bowel, rectum and anus, and the forming of a stoma).

When I reflect on my health and Crohn's during this period, I feel to extent it is true to say that ignorance was bliss. I knew people with my condition often needed surgery later in their life. I also had a vague idea that after surgery there might be the need to wear a 'bag'. But I didn't want to worry myself by knowing anymore than that. I was in my own room in the hospital when the consultant told me what a pan-proctocolectomy operation involved. I remember feeling very upset and terrified of the surgery. After the consultant left I frantically Googled both the procedure and information on what exactly a stoma was. I found lots of videos on YouTube that were really helpful, showing how to clean a stoma, put a bag on securely and how to wear support garments to prevent a hernia forming. Two weeks later I went down to theatre. Rather than having the pan-proctocolectomy, it was decided I would retain my large bowel and have a loop ileostomy formed instead. This type of stoma was formed so that if all went well, biological drugs would over time 'heal' my inflamed large bowel, while 'traffic' as I like to think of it was diverted to pass through the stoma rather than the large bowel, thus resting it. Despite the initial shock of needing surgery, I remained positive, especially as the plan at this stage was to have a reversal later down the line.

CONTINUED ON PAGE 21, COLUMN 1



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CONTINUED FROM PAGE 19, COLUMN 2

Sadly, this wasn't to be and, after trying various biological drugs, in March 2017 I found myself back in theatre where I underwent a pan-proctocolectomy and had a permanent or end stoma formed.

I am grateful that I had the chance to try other biological drugs before my second bout of surgery. At least this way, I know I explored all the options before making my stoma permanent. My gastro and surgical consultants were less optimistic and in fact suggested the second operation long before I agreed to go ahead with it. But as it was such a final operation, I wanted to give modern drugs a chance until, that is, it became clear it was unsafe to keep doing so.

Although it took me time to adjust to living with a stoma, there is no doubt that it has given me back my quality of life and enables me to live an active and fulfilling lifestyle. I work Monday to Friday in a busy office and sometimes support events at the weekend. I usually go to the gym before work and also enjoy running and exploring the countryside with my husband and our dog. I volunteer with Girlguiding and a local Arts committee and enjoy crafts like cross stitch, making cards and découpage as well as live music and theatre. The only real changes I have had to make in my new life with a stoma are that I'm careful when exercising. This is because I developed a hernia during my first operation, which I had repaired in

the second. I wear a heavy-duty support belt when walking my powerful dog or doing something like circuits. I also find swimming is a great form of exercise as the water naturally supports you. I am also conscious of what I eat at times. Not all the time – just before something major, like a long-haul flight or a full day out when I don't want to constantly be emptying my bag. I have found that Imodium tablets help here, as they slow down my output. I also have sachets that I put in my bag to help soak it up.

Reading the above, you will have probably got the impression that I have adapted well to having a stoma. To extent that's true, but let me tell you now, it didn't stop me worrying about my wedding! So, I will finish by telling you about how I prepared. My two biggest considerations were my dress and ensuring that my stoma behaved on the day.

I knew that I wanted a fairly sleek and skimming dress that was flattering to my figure. I was determined not to feel like I had to compensate or compromise on this due to having a stoma bag. I usually wear a belt that clips onto my stoma bag and then a support band which varies depending on the activity I am doing – for everyday use I wear a light support tube which keeps my stoma from prolapsing and keeps my bag streamlined under tighter fitting clothes. On my wedding day, to reduce visible lines through the dress fabric I didn't wear the belt that clips onto my bag or the support

band. Instead I opted for some support underwear so I could be confident dancing on the night. All our guests knew I had a stoma and wore a bag, but I had lots of comments on the day that you wouldn't have known about this. People who have seen the photos have said the same. I'm not ashamed of my stoma, but I didn't want it detracting from my dress on my big day or forcing me to compromise on the style of dress I wanted.

To help ensure that my stoma behaved, I chose a slightly tweaked menu from our guests, just to ensure that the food was a bit more manageable for me on a long day/evening. I swapped mash potato for roast and went for something other than soup as a starter, as this can sometimes make my output more watery, meaning I have to empty my bag more often. I also tried and tested the meal the evening before the wedding and then on the day itself, I had scrambled eggs on toast for breakfast as I knew from experience that the consistency of output from this would be manageable.

The day went flawlessly and, like most days, I pretty much forgot I had a stoma. I'm able to still enjoy alcohol which was great, as this meant I could 'actively' take part in all the toasts. I had my bridesmaids to help navigate trips to the ladies, including keeping my white dress out of the way when emptying my bag. My message to all would-be brides out there is simple: go for it! Show your stoma who is boss and have a fantastic day! ■



Your letters and e-mails

Ed's note: Despite the unusual circumstances in which we currently find ourselves, the *Tidings* mailbox wasn't completely empty. For the first time in a while, it contained tips from a couple of our readers. Additionally, just before the scale of coronavirus problem started to emerge and countries began to impose restrictions on travel, we received a very upbeat letter on foreign travel, complete with some super snaps. I hope the one we have featured will lift rather than dent your spirits!

Dear Editor

For some time, my biggest problem with having a stoma was leakage.

I wear a two-piece flange and pouch. I am very careful placing the flange over the stoma correctly. I had the stoma care nurse measure my stoma, asked the supplier of my medical supplies to ensure my flanges were pre-cut so that no mistake was made in self cutting.

It didn't seem to matter what flange I tried, I experienced leakages from under the flange, seepage from the sides of the flange and even the whole flange coming loose.

I became reluctant to go out – just in case I had an accident. Night-time was another time when I became anxious, never knowing if I would wake up with a problem.

AND THEN a letter was printed in *Tidings* about an ostomate that had experienced leakage but found the answer to the problem.

The answer is a dog training mat.

As I don't have a dog – I had no idea what this mat could be – but a quick "google" and the answer was a waterproof lined square mat of light material that puppies are encouraged to pee on while being toilet trained.

The idea is to cut the square of puppy mat into a size suitable to cover the area of your flange and therefore contain it behind this waterproof wall. So, I started by cutting the mat into four pieces – I have since learnt to use less but this was my first attempt. I then covered the whole area of my stomach – covering the flange and pouch. My pants, support garment and tights ensured that the mat stayed in place.

I chose to go out for a few hours and felt confident that should the flange leak it would be well contained behind this "wall" of mat. Success. I did not leak. Was this because I was more relaxed or just a coincidence?

The first night was also a success. I slept knowing that if I did get woken up by an accident it would be contained: no messy clothes, no bed linen soiled and no midnight bath and clean-up session.

I have continued to have leakage – during the day and at night. Mostly due to over exertion during the day – and too many chocolates and bad diet in the evenings. But I no longer have a

problem managing the leak. If there is a problem, I gently slip a disposal bag under the bag, flange and mat – (while still on my skin) contain the lot as I remove the flange and into the bag goes every part of the mess. I clean up myself, place on a new flange and pouch and I am back in bed in 15 minutes – all neat, tidy and spotlessly clean. I use a Tommee Tippee nappy dispenser so the disposal bag is neatly wrapped away and the bathroom returned to a clean and pleasant place.

I don't know who wrote in to tell everyone about this problem solver, but it has changed my life.

I have full confidence while I am out and about. If I have a leak – the same clean-up procedure takes place – gently place the disposal bag under the pouch and flange and mat – fold it all into the bag – clean up and after replacing the pouch go on your way with nothing on your clothes, clean and fresh.

I can't express how much this has changed my life. I am now free from anxiety and I have full confidence that my flange is contained and safe. I have even started having leakages less frequently as I feel more relaxed and in control – a thought transmitted to my brain!

Thank you to your writer for sharing such a wonderful answer to the problem of leakage.

Yours sincerely
Edith B

Ed's note: The letter Edith refers to was submitted by Sue Hatton and appeared in the winter 2018/19 edition. Edith is not the first to have found Sue's tip useful!

Dear Tidings

I keep reading a lot of people asking questions regarding travel, what is possible with a bag and hidden disabilities etc. so I thought I would share a little trip I have recently been on to hopefully inspire others who may be a little worried or concerned about foreign travel.

I don't see having my stoma as a hidden disability and never use disabled toilets unless I need to change the bag as the extra space comes in very handy. Instead, I see it more as a hidden pain in the side, but only sometimes and I'm certainly aware if you give your stoma a chance to rule you it will do its best and take over your life.

I am a very active person and do lots of swimming, hiking, weeks away in the mountains at times but this last trip to the Maldives was one of my most memorable.



My wife and I had the fantastic opportunity to be marooned on an island for a day in the Indian Ocean with only a satellite phone for emergencies and spent the whole day, swimming with large black tip sharks, massive manta rays and generally sunbathing and chilling out. Although after one 1.8m shark kept following us for around an hour it certainly made my wife nervous and she was always on lookout. It even had me thinking can it smell my bag ha ha.

One thing having a bag for life has given me is the utmost determination to live everyday smiling and being kind to others. We all cope with things differently and everybody has problems to deal with. But, however big or small these problems may seem, I try my hardest to stay positive and see the good side of every person or situation. Even if it's a dark dull day, I do my best to smile and think: 'at least it's a great day, it's just a darker day than usual.'

If we ask our stoma what it has given us, the only answer possible is LIFE, which in anyone's book is a great gift to receive.

Feel free to follow my world travel and adventures on social media as: ileostomy on tour, where I'm showing the world that having a stoma does not mean we cannot have a life.

Glen Neilson

Dear Tidings

Good Day fellow 'bums on tums'! I have a tip that some might like to consider.

When I left hospital, my stoma nurse recommended doing bag changes standing in front of the hand basin, with a nappy sack type disposal bag hooked over the tap head, in which to put all the various used materials. However, I found that my stoma has a mind of its own especially when being cleaned! Hence doing as she suggested meant that sometimes a complete clean of the

hand basin was required...strangely something my wife insisted on!



But I have solved the problem. I now use a plastic tub like those used to pack washing machine tablets. I make two holes towards the top left and right of the tub. These fit the tabs on the elasticated belts you can get to help hold your bag against your stoma (see photo above). I then place the belt and tub around my waist with the disposable bag inside, directly below my stoma bag. By doing this, I can remove my stoma bag, clean, and fit a new bag and place all the waste in the disposable bag. I then seal and dispose of this as normal. My method, or 'tip' also allows me to move about if necessary, without worrying about depositing any 'material' where it's not welcome!

I hope this might be of use to some of you, in an ideal world if this tub could be made collapsible (as in flat) then it would be so much easier to take out with you and change whilst out in public toilets maybe without the need to undress completely.

Roger Langton



We look forward to hearing from you, our readers:

Send an e-mail to: info@ColostomyUK.org

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

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

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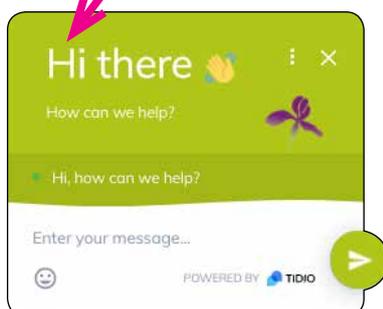
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See our main advert on page 28.

We have to create

Keely C

When I received my ostomy, it was not life ending, it was not the 'worst case scenario', it was life changing yes, but I could once again live.

In my teens I got accepted into a prestigious dance college in London. A few months after starting I began having excruciating stomach pains, then I would be sick whenever I ate anything, even baby food. My weight plummeted and it was only when I began to look sick, the doctors took me seriously.

I fought so hard for a diagnosis and was eventually misdiagnosed with anorexia and bulimia. I was told I would be sectioned if I didn't start eating and putting on weight. I was prescribed hypnotherapy sessions, counseling...

When I tried to fight harder to get a diagnosis that fitted my symptoms, I faced many unprofessional doctors who told me, "you are just crazy, mentally ill", which is incredibly wrong in all aspects. My amazing mum took me to nearly every single hospital, NHS and private, that she could, until someone would listen and do the correct tests. We finally came across a doctor who told me I did not have an eating disorder. He did a simple x-ray and found my intestines, for use of better words, "were in a huge muddle". I was

given morphine for the pain, and I was scheduled for a small, simple surgery the following week. I was still attending dance college, now just watching and only going in the mornings before the pain got too much and to avoid the embarrassment of passing.

When I had my first surgery I woke up feeling like something was wrong, and indeed it was. My body rejected the mesh they inserted and I was back to square one but worse. Too-many-surgeries-to-count-on-my-fingers later over the course of just over a year, I found myself in the Surgical Emergency Unit, my "last chance" was a permanent ileostomy. I waited three weeks on that ward to have the operation, it was lonely, it was painful, but it was a step closer to a better life. And a better life is exactly what I got, after two years of misdiagnosis, a year of operations and a lifetime of scars, finally healing.

After the ordeal was hard, the one thing that kept me going was my newly placed ostomy, my safety net, the thing that saved my life. Mentally and physically the first couple of years following were tough. I started back at the gym and became one of those 'gym rats'. This helped me a lot initially to accept my new self, but it was a band aid not a long-term solution. Pain was the norm for a very long time, and 'good' pain in the gym felt like a strange comfort zone.

An incredible acting and life coach told me to focus on what I could give...I didn't think



e to create change

at Wells



I could. I thought I was so tarnished I might as well keep myself to myself, but slowly and surely, I understood the concept which now serves me every single day of my life.

Sometime later, I ended up in hospital again due to complications with my stoma and it had to be re-sited. It was then I started an Instagram page to share and vent my experiences with invisible illness, surgeries and to find people like me. One day I got a message from a girl who was on the ward below me in the same hospital. I went to go and see her and it was a best friend match made in heaven. If it wasn't for her, our ostomy journeys would have been much more difficult. We were both young women who missed out on 'normal' teenage life, both dancers, who were both misunderstood, not listened to and were both misdiagnosed.

Soon after, I got a job in a talent agency, initially interning then taking over as the lead children talent agent. Then I got into business, making connections in the finance world and throwing myself headfirst into working and thriving in places I could not before.

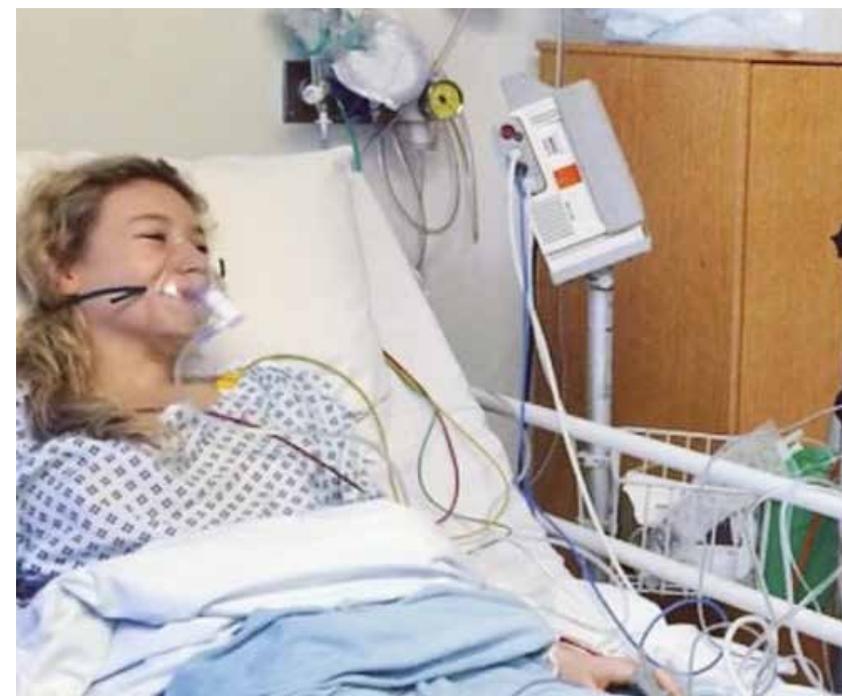
Giving, was the way forward, but I also needed to learn how to give to myself. I started to lose my sense of how much I enjoyed performing, so I took a trip to Los Angeles, a scary prospect, flying for the first time on my own after surgery, the first time with a stoma and my medical requirements that a foreign country might not be able to

cater for too, but I took the plunge and did an acting course that was a huge milestone in my life. I stayed out there many weeks longer than expected and lost my job back home, so I came back to the UK, started my own talent agency and began the visa process.

A year later I moved to the USA, I expanded my UK company to LA and we represent D/deaf, disabled and minority artists. I made it very specific to representing talent that had been under served and viewed, because I was sick and tired of being treated like I was less in the industry: for instance I got told couldn't wear a bikini on a TV and film because it was "too off-putting" for the audience. I knew that others were in the same boat, others who lived, looked and engaged a little different to what Hollywood was used to. I am now an actress, producer and the CEO of three international companies. I am also working on building my own major film and TV studio that will be the world's first studio fully accessible for people with disabilities as well as being carbon neutral (and run by a female entrepreneur).

I believe to change to society we have to learn to tell and listen to a new set of stories about the world that we want to create.

We have to create to create change. ■



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My strange journey to a colostomy and beyond!

Melvyn Wilkins



This is a story about my incredible journey following my bowel cancer diagnosis. Not necessarily a good journey in places, but still a journey that I had to do and afterwards came out in a good place. Some of this may scare readers but that's not my intention. Believe me when I say, "it was worth it", the alternatives didn't bear thinking about.

Early in 2016 I had a urinary problem while away on a weekend break. It was very difficult to urinate for a couple of days but then cleared up within hours. I thought no more about it until several months later when it happened again. This time I went to my GP who said, after examination, it was probably an enlarged prostate. He prescribed me a drug and organised a consultant visit to carry out a urinary tract endoscopy. This was not a lot of fun but did confirm my prostate was enlarged and so I continued with the medication.

In 2013 I was 60 years old and ditched my first bowel cancer screening test. I did the same again in 2015. Mid-2017 I had another occurrence of urinary problems and went back to my GP once more. This time he suggested I have a CEA blood test and also booked me in for an endoscopy. Feeling OK again after two days I had no concerns.

I went for my endoscopy at Gloucestershire Royal Hospital (GRH) in late May and everything seemed OK with the endoscopy until the doctor said he had found some polyps. He took some biopsy samples and then hit me with the fact that one of them seemed harder than the others and may be cancerous. Further testing was required to confirm or deny this. As we were about to go off to France for a two-week holiday, I requested they hold off telling me the result until my return. After getting back home and a little concerned I carried on as usual until I received a phone call from the GRH colorectal nurse, who confirmed it was a cancerous growth. I was booked in to see a consultant. At this stage I was still quite upbeat about the whole scenario and remained very positive that the outcome would not be too scary!

There then followed a colonoscopy, CT scan and then an MRI scan, and on 26 September 2017, I had a meeting with the colorectal consultant. The outcome wasn't that good, I had an anterior tumour reaching down and involving an anal cushion. Her view was that I should have an abdomino-perineal resection (APeR), which would leave me with a permanent colostomy. I was asked if I wanted a second opinion but declined, putting immense faith in the consultant.

It was a very silent journey home with my wife that afternoon. Although I was prepared to accept the colostomy, she was horrified at the thought of it. I was an active, fun loving 64-year old. Her fear that this might change forever was a huge hurdle.

By a weird coincidence the following Sunday our newspaper carried an article relating to a new type of surgery that was suitable for early stage bowel cancer. My wife being so proactive, tracked down the professor in London who had trialled the new procedure and promptly emailed him asking for advice. In the meantime, we had another short break in France, but it was very subdued.

In early October we received a response from one of the professor's colleagues at St Mark's Hospital in Harrow. He wanted to see all my scans, etc and then arrange an appointment to see me privately, which he then did under the NHS. He also requested another sigmoidoscopy and then a further sigmoid/gastroscopy at the London Clinic, which was done privately. A meeting with the consultant at St Mark's also took place and his conclusion was that the APeR was probably the best option for ongoing quality of life. He also felt the surgery could be satisfactorily performed at GRH and that there was no need to have it done at St Mark's. An interesting fact, which I can't substantiate, is that he said bowel cancer can remain undetected for many years before any problems arise. He said ten years wasn't unusual and when I said I was concerned over the time it seemed to be taking to get things moving, he said it wouldn't make that much difference, my cancer was at the T1/T2 stage.

Feeling embarrassed and a bit let down(!) I then had to go back to the consultant at GRH and ask her to take up my case once

CONTINUED ON PAGE 33, COLUMN 1



Scams

Unfortunately coronavirus related scams are on the rise.
The following advice comes from National Trading Standards*.

Doorstep crime:

- Criminals targeting older people on their doorstep and offering to do their shopping. Thieves take the money and do not return.
- Doorstep cleansing services that offer to clean drives and doorways to kill bacteria and help prevent the spread of the virus.

Online scams

- Email scams that trick people into opening malicious attachments, which put people at risk of identity theft with personal information, passwords, contacts and bank details at risk. Some of these emails have lured people to click on attachments by offering information about people in the local area who are affected by coronavirus.
- Fake online resources – such as false Coronavirus Maps – that deliver malware such as AZORult Trojan, an information stealing program which can infiltrate a variety of sensitive data. A prominent example that has deployed malware is ‘corona-virus-map[dot]com’.

Refund scams

- Companies offering fake holiday refunds for individuals who have been forced to cancel their trips. People seeking refunds should also be wary of fake websites set up to claim holiday refunds.

Counterfeit goods

- Fake sanitisers, face masks and Covid-19 swabbing kits sold online and door-to-door. These products can often be dangerous and unsafe. There are reports of some potentially harmful hand sanitiser containing glutaral (or glutaraldehyde), which was banned for human use in 2014.

Telephone scams

- As more people self-isolate at home there is an increasing risk that telephone scams will also rise, including criminals claiming to be your bank, mortgage lender or utility company.

Donation scams

- There have been reports of thieves extorting money from consumers by claiming they are collecting donations for a Covid-19 ‘vaccine’.

Loan sharks

- Illegal money lenders are expected to prey on people’s financial hardship, lending money before charging extortionate interest rates and fees through threats and violence.

*Advice correct at time of press.



CONTINUED FROM PAGE 31, COLUMN 2

more. She started to prepare for the surgery as soon as possible but in view of the remarks about timescales made at St Mark's I asked if I could at least get through Christmas first. Surgery was consequently planned for 10 January 2018.

The surgery went according to plan and I felt relatively OK on returning to the ward, but here things started to take a turn for the worse. Waiting for my stoma to 'fire up' and getting all the drips and tubes out of me was a concern, and this was part of the problem... "Mr Stoma" decided he wasn't going to play ball. On day three I got out of bed and collapsed on the floor, someone pushed the panic button and I came to, surrounded by medical staff. The reason: almost kidney failure as not enough fluids. They then gave me an x-ray and CT scan from which it appeared my bowel had an adhesion so it wouldn't pass anything. On 18 January I went for further surgery to clear the blockage.

I pull no punches here, this is when it started to get tough. My wife visited every evening after work, a 30-mile round trip. I looked awful and it transpires she thought I was dying. My stoma still failed to work so they stopped feeding me and drained fluids from my stomach and fed me intravenously. I ended up losing 22kg and growing a full-scale beard. This continued for four weeks until one morning all hell let loose...my stoma had started working! I was home within 24 hours.

So what since? The wound sites took ages to heal and I have had two abscess breakdowns. One site is still being dressed daily after two years. I went back to GRH in August 2019 for some reconstructive surgery on my APeR site but then the keyhole site got infected. It wasn't painful or uncomfortable, just a daily task to change a basic dressing. I saw the consultant again in February 2020, following a sinogram in January to determine the depth

of the abscess track, and she said a further bit of reconstructive surgery may be needed. However, my GP nurse suggested they try a PICO negative pressure dressing instead. As I write this, it's my first week.

I have gone through life being a pessimist, but strangely positive thoughts got me through all this. I can honestly say I never gave up hope, some may say I was too blasé. Another thing that I think helped was talking about it: what was happening, how I felt and what my plans were. What strikes me most is how many others are having or have had the same journey. By talking about my journey, I discovered that two of my friends from the '80s both have stomas, along with two women in the local co-op and others that I used to work with. There are also people my wife knows, including even her uncle. Unless they tell you then you just don't know. Furthermore my employer was brilliant, offering to put my wife up in a hotel either in London or Gloucester should that be necessary. Not many employers would do that!

I am still an active 66-year old now, walking almost every day in the local Forest of Dean and committed to helping others through delivering for the meals on wheels service. My wife has come to terms with my changes and we have travelled extensively since 2018. Yes, there are limitations, but we have found ways to overcome them. She is younger than me and still works, so I have become a master chef too. Fortunately, my stoma is good enough to let me challenge myself with every meal without any concerns – curries included!

I hope this story helps others who are either at the initial stages or getting over the changes, it really isn't that bad. And, I have one joke that I use regularly: I don't suffer from piles anymore!

The journey continues... ■

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24/7
Stoma Helpline
0800 328 4257

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

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

www.ColostomyUK.org

Dear nurse

We don't get many calls to our 24-hour Stoma Helpline about stoma stenosis. In fact, I suspect that many readers won't even have heard of the condition. That's why I was so delighted when Karen Totty, who is a Stoma Care Nurse Team Leader at Fittleworth Medical Ltd, offered to write about it for us. So read on to learn more about everything from the causes and symptoms of stenosis to the treatment options available.



Understanding stoma stenosis

Following stoma surgery of any kind, whether it be for Colostomy, Ileostomy or Urostomy, there are a number of complications that can occur. Some are more common than others, with stoma stenosis being one of the less frequent complications. It generally occurs in the first few weeks following surgery but can occur in established stomas.

What is stoma stenosis?

Stenosis comes from an ancient Greek word meaning narrow. In medical terms, stenosis is an abnormal narrowing or stricture of a tubular organ or structure.

Stoma stenosis is the narrowing of the outlet of the stoma which results in impairment or obstruction of drainage of faeces or urine. The narrowing can occur at skin level where there will be visible signs of constriction of the stoma opening or the skin around the stoma, making the stoma opening much smaller and almost closed. Alternatively, it can be below the skin level with the stoma appearing normal on the surface but with output from the stoma altered or reduced.

What causes stoma stenosis?

- ❖ Excessive scar tissue that has formed around the stoma opening due to separation of the bowel from the skin, which may have been caused by severe inflammation or infection.
- ❖ Radiotherapy prior to surgery.
- ❖ Stoma construction techniques which result in an insufficient opening to bring the stoma through or inadequate suturing.
- ❖ Pre-existing conditions or treatments which may affect the healing process and result in separation at the border

of the skin and bowel. Inflammatory bowel disease, poor nutritional state and obesity for instance, can put the bowel under extreme tension, causing the bowel to separate from the skin and retract below skin level.

- ❖ Tumour deposits around the stoma opening or behind it.
- ❖ Trauma.

What symptoms may I experience?

Ostomates with a urinary stoma (urostomy) may experience a consistent decrease in urine output; urine being expelled under pressure; pain in their left or right side over the kidney area and recurrent urinary tract infections.

Ostomates with faecal stomas (colostomy and ileostomy) may experience a range of symptoms dependent on the severity of the stenosis. These may include: a reduction in output; increase in wind; passing narrow ribbon-like faeces or liquid stool; explosive output; pain around the stoma opening when passing faeces; abdominal cramps and bloating of the tummy and nausea or vomiting.

CONTINUED ON PAGE 37, COLUMN 1

If you have stoma stenosis and want to talk to a fellow ostomate that has experience of the condition too, then please don't hesitate to call us. We will do our best to find a volunteer who can help!



Colostomy 

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Surname:	
Address:	
Postcode:	
Tel:	Mobile:
D.O.B.:	If you would like to receive correspondence via email, please tick here <input type="checkbox"/>
Email:	
<input type="checkbox"/> If you do not wish your name to be publicised if you win, please tick here	

2. Payment Frequency

How many entries would you like each week?

How often do you want to pay?	<input type="checkbox"/> Monthly	£4.34 Direct Debit only	X
	<input type="checkbox"/> Every 13 wks	£13	
	<input type="checkbox"/> Every 26 wks	£26	
	<input type="checkbox"/> Every 52 wks	£52	
(please tick payment frequency and write amount in box)			=
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Address:

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

Signature: Date:

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

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

Post this form in a stamped envelope to:

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

For office use only:

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CONTINUED FROM PAGE 35, COLUMN 2

Stoma stenosis can lead to blockage of the bowel.

What do I do if I have a blockage?

If you think you have a blockage due to undigested food try the following:

- ❖ Don't eat anything at the moment.
- ❖ Drink plenty of fluids, warm drinks sometimes help.
- ❖ Gently massage the tummy especially around the stoma.
- ❖ Take a warm bath if you feel safe to do so.
- ❖ Lay on the bed with your knees bent and feet flat on the bed, roll gently from side to side.

If your symptoms aren't subsiding after a couple of hours then you must seek urgent medical attention!

How is stoma stenosis treated?

Further surgery may be required if the narrowing of the stoma is so severe it is causing a blockage/obstruction of the bowel.

In less severe cases the stoma stenosis can be managed conservatively as follows:

Colostomists and Ileostomists:

- ❖ Eat a low residue (low fibre) diet as well as avoiding skins, seeds, nuts, coconut, sweetcorn and other foods that may be hard to digest fully.
- ❖ Chew food well.

- ❖ Drink plenty of fluids.
- ❖ Colostomates may be advised to take a stool softener to prevent blockage.
- ❖ Your stoma nurse will provide advice.

Colostomy, Ileostomy, Urostomy:

The surgeon or stoma care specialist nurse may recommend dilating the stoma opening, especially if it is not appropriate for more surgery to take place. The stoma care nurse will make an initial assessment of the narrowing by inserting a gloved, lubricated finger into the stoma opening, generally with the smallest finger. The stoma care specialist nurse can teach the ostomate to dilate the stoma once or twice a day using either a gloved finger, starting with a small finger then moving on to a larger one or using a metal or plastic dilator again increasing these in size, starting with the smaller one and moving on to the larger one. The use and frequency of these will be determined by your surgeon or stoma care nurse. If the stoma dilation keeps the stoma open enough for it to function adequately then surgery can be avoided.

It can be quite distressing and frightening when dealing with a stenosed stoma but your stoma care nurse will give the support, information and guidance you need to build confidence in managing the stoma effectively. ■

Ed's note: Please keep those questions coming as we depend on them to run this feature. Any stoma-related questions that you would like to put to a stoma care nurse, surgeon, dietitian or other healthcare professional will be gladly received. You can e-mail these to editor@ColostomyUK.org or send them by post to:

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

2020 Raffle – get your tickets now!

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Detach and return this with payment to the address below.

First name

Surname

Address

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Postcode

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Please return payment, ticket stubs and unsold tickets no later than **Friday 16 October 2020** to:
Colostomy UK, Enterprise House,
95 London Street, Reading, RG1 4QA.
Draw to take place on: **19 October 2020**
at Colostomy UK, Enterprise House, 2nd Floor,
95 London Street, Reading, Berkshire, RG1 4QA.
Late entries will be treated as donations.

£1
Ticket
10 per book

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Keep this portion for verification.

Annual Prize Draw



Supporting and empowering ostomates

1st Prize

£2,500

2nd Prize

£1,000

3rd Prize

10 prizes of £100

Draw date: Monday 19 October 2020 around 12:00noon
at Colostomy UK, Enterprise House, 2nd Floor, 95 London Street, Reading, Berkshire, RG1 4QA
No tickets may be sold by or to anyone under 16 years. No tickets may be sold on the street.
Promoter: Mr Giovanni Cinque, Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA
Winners will be notified by telephone, email or post and announced in the Winter 2020 edition of Tidings
Colostomy Association t/a Colostomy UK is a charity registered in England and Wales No: 1113471 Lottery Licence no: LOT000141

Every ticket purchased helps us to support and empower more ostomates

The Colostomy UK Annual Prize Draw gives you the chance to win £2,500!

A book of 10 tickets is enclosed to start you off. If you want more please get in touch. Tickets are only £1 and all money raised from the raffle will go towards supporting vital Colostomy UK services such as our 24-hour stoma helpline, free literature and Tidings magazine. Simply fill in your details on the tear-off slip and post this section back to us along with your payment. It couldn't be easier.

Every ticket purchased helps us to support and empower more ostomates.

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All profits raised from the following items help us to support and empower ostomates. You can complete your order by returning the form below or visiting:

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Jackie's Story

Jackie Butterworth



Hi my name is Jackie. I wanted to share my story in the hope that it will help people who are perhaps struggling to come to terms with having a stoma. I have been through some tough times over the past five years, but have come out the other side, thanks

to the support I have received from all different people. By way of background, I am 51-years old and have suffered from depression for many years (for which I take medication). I have had my stoma since 2014.

Life seemed to tick along for me until 2013 when I got ill with what I thought was an upset tummy. Over time the pain got worse; I was always on the toilet with loose bowels and I could not even go out. In the end, I went to see my GP who referred me to the hospital, but before my appointment came through I got worse and ended up having to phone an ambulance, which rushed me into hospital.

After a few days of scans, blood tests and a flexible sigmoidoscopy (which was so painful I thought they were ripping my tummy out), the doctor told me I had ulcerative colitis. I was terrified and confused and I just wanted to go home to my son and husband. After a few weeks in hospital I was sent home on medication with appointments arranged to see the IBD nurses.

Things went back to normal for a while, but then the medication stopped working. I was put on infliximab infusions, but things started to go from bad to worse. I had a massive flare-up. It was so bad that on some days I couldn't even take my son to school because I couldn't get off the toilet. Going out was a total nightmare, I had accidents and the pain was so bad I made the decision to ask the surgeon to remove my colon.

The appointment with my surgeon was in 2014, it was a Monday. On the Thursday I was admitted and on the Friday morning I was taken down for the operation. The night before, my medical team explained what was going to happen, but I don't think anything could have properly prepared for that moment when I came round after the surgery. Back in the recovery room I woke up to find a bag attached to my tummy. I remember the first time I saw my stoma (Billy), I was completely heartbroken. I know that having 'him' saved my life, but he was dirty and horrible and having struggled with my self-image for many years, I just hated myself even more.

These feelings remained with me in the post-op period and beyond. This didn't help my marriage which, by this stage, was suffering. There was no physical relationship between me and my husband. I felt dirty and was completely terrified of my bag leaking during intimate times. I was lonely too and had no one to talk to. My husband didn't understand at all. He used to say: "If I got one done I would be grateful because it saved my life". Of course, that was true, but what he couldn't comprehend was that there was more to it than that; it's a complete lifestyle change.

I soldiered on in the years that followed. On many occasions I was admitted to hospital with blockages. I also had an infection that resulted in me having half my tummy cut away and leaving me with bad scar tissue which, in turn, caused a lot of leaks. Then in 2017 I found out the ulcerative colitis had come back in my rectal stump. My surgeon said it would be for the best to have it removed. After that surgery we went into 2018 looking forward to things getting back to normal: no surgery and trying to get well.

Then one day in the October my husband came home from work, I was upstairs and after a row I asked him if he had someone else. To my horror he said: "yes". My world fell apart as he stood there and told me he no longer loved me and did not want to be with me anymore. With that he left.

A week later I had a phone call from my landlady who told me that me and my son had to be out of the house by the January. When I asked why, she said that she didn't want anyone who was claiming benefits living in her house. My already dark mood got darker still and I started to suffer badly from anxiety. I stopped going out, my stoma was leaking all the time, I was sore, and I hated myself. If it wasn't for my son, I wouldn't be here today.

It was then that I met Tracey Leese, the stoma nurse for my area and she was amazing. She didn't just help with the practical side to my stoma care but she sat with me and listened whilst I talked. This simple act of listening and understanding and caring marked a turning point. I started going to a group called Friendship Friday at Community House in Selby. Here I began to meet some incredible people who wanted to spend time with me and help me. This was something I was not used to. Through Community House I joined the trauma group BVocal, run by Chris Haily-Norris, Emily Havercroft and Jon Moses, who work with a small group of people with different traumas. The course provided a safe environment where we could talk and work through our traumas. We also did art work. At the end of the course we had a gallery to show off the work we had done. Mine was about my journey, my main one was with my stoma.

The therapeutic value of art is well recognised. At **Colostomy UK** we deliver Creative Minds arts sessions via support groups. If you run a support group or attend a support group and would like to find out more, then please drop us an email: info@ColostomyUK.org or call our admin line on **0118 939 1537**.

Up until this point I had never told anyone except family and a few close friends what I had been through. But thanks to Tracey Leese and the people I met at Community House, I have very slowly built the confidence to open up about my life and share more freely with people what has happened to me. I have learned that there is nothing to be ashamed of and that there are people who you can trust and do want to help. Life with my stoma is very different now. I have started to like it and I am no longer ashamed of having one. If anyone wants to ask questions or even have a look, I am very happy to share. I am even starting my own stoma group which is a huge thing for me and so out of my comfort zone. I have a long way to go but I am getting stronger all the time. I am doing different courses, I see a therapist every week, I even volunteer for things!

My son and I have a new home and we are starting to settle down and move on with our lives. Things are not 100% but compared to this time last year I have come on leaps and bounds. I am even starting to like myself a little some days it is really hard, but I push myself all the time. I now realise that I am in control of my stoma and its care, not the other way round. So, to all of you who are really struggling right now and think no one can help: I am living proof that there is a light at the end of the tunnel. ■



Colostomy UK: active ostomates®



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

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

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

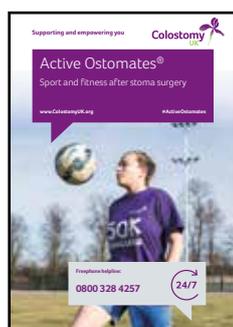
In this edition, our Active Ostomates feature has a slightly different focus. With the coronavirus forcing us to self-isolate, we thought we'd look at things you can do to keep yourself physically and mentally active at home.

The sudden adjustments we have all had to make has impacted our daily lives in many ways. It's certainly much more difficult to be as mobile as we were. It's therefore crucial to keep physically active and avoid the pitfalls of dropping into a sedentary lifestyle.

It is generally accepted that we need to be active for a minimum of 30 minutes a day and at least two of these days each week should involve strengthening exercises.

Being active on a regular basis has a number of benefits including:

- ❖ Reducing your risk of a heart attack.
- ❖ Helping you to better manage your weight.
- ❖ A lower blood cholesterol level.
- ❖ Less risk of type two diabetes and some cancers.
- ❖ Lower blood pressure.
- ❖ Stronger bones, muscles and joints and less risk of developing osteoporosis.
- ❖ Reducing your risk of falls.
- ❖ Quicker recovery times when you have been ill.
- ❖ More energy.
- ❖ Exercise may also change levels of chemicals in your brain, such as serotonin, endorphins and stress hormones, leading to a brighter mood and improved sleep patterns.



Colostomy UK's very own *Sport and fitness after stoma surgery* booklet includes a series of exercises that encourage core strength and can be repeated daily. Each of them works deeply, increasing the strength of your back and stomach muscles, helping to reduce back and posture problems as well as the risk of post-operative

hernias. They can be performed on the bed, lying on a thick mat so that your spine is gently cushioned, or sitting on a chair. Some can even be done while you are watching the television! This makes them ideal for keeping fit while you stay home and safe during the coronavirus outbreak.

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

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

Information and guidance from the NHS

The NHS website has some great exercises that you can try safely in your home too. Just go to: www.nhs.uk/live-well/exercise/easy-low-impact-exercises/ and scroll down the page to the section called 'Home Exercises'. There are a range of activities that have been split in to four sections: Sitting, Balance, Flexibility, and Strength.

If you're able to, it might be a good idea to try a different group of exercises each day so the exercises don't get too repetitive.

The Green Goddess is back!

For those of you that can't access the internet don't worry there are lots of other ways get ideas on how to be active at home, including the return of the Green Goddess!

Diane Moran the original keep fit queen of the 1980s is back on air three times a week on BBC Breakfast with workouts that viewers can follow along at home.

The One Show (BBC1) is also dedicating air time to keeping viewers informed with regular keep fit and healthy eating tips. They are also providing links to other BBC output that can help and support, while BBC Health Check UK Live directly addresses the concerns of viewers who are in isolation, offering tips on how to keep healthy and happy at home.

Walking

At the time of going to press, it was still permissible for symptom-free people to take outdoor exercise once a day (provided they were not in the vulnerable grouping and provided no-one in

#ActiveOstomates

their household had Covid-19 or was displaying the symptoms of it). Walking is an excellent way to maintain your health and wellbeing. But please check the government's latest coronavirus advice before you go, in case this has changed. Walkers must also stay more than two metres from others. Please see Public Health England's guidelines on social distancing.

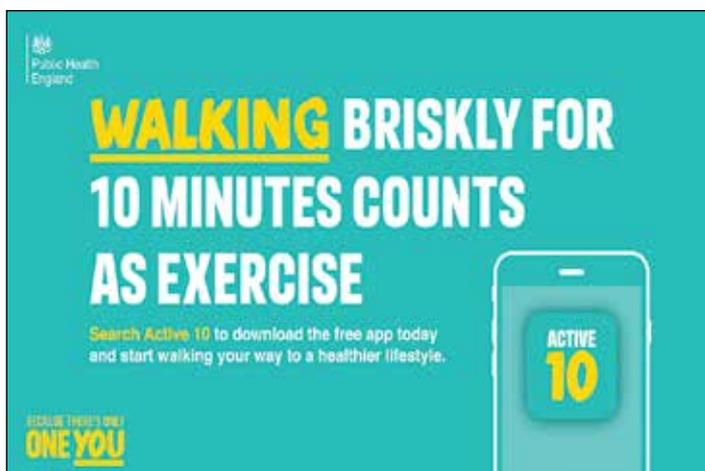


Walking is simple, free and one of the easiest ways to get more active, lose weight and become healthier. It's sometimes overlooked as a form of exercise but brisk walking can help you build stamina, burn excess calories and make your heart healthier.

You don't have to walk for hours either. A brisk 10 minute daily walk has lots of health benefits and counts towards your recommended thirty minutes a day of exercise.

If you're not very active but are able to walk then start slowly and think about increasing your distance gradually.

You can also get more information on walking from the NHS ACTIVE 10 website



<https://www.nhs.uk/oneyou/active10/home>

Remember doing any physical activity is better than doing none. If you currently do no physical activity, start by doing some, and gradually build up to the recommended amount, and be active on most, preferably all, days every week.

Green fingers

Many of us also have a great tool to improve both our physical and mental well-being right on our doorsteps and might not even realise it...gardening is a source of relaxation, comfort and enjoyment for millions of people around the UK, and can be hugely beneficial to our health.

Get digging! It needn't be about heavy digging, but gardening does put you through a range of movements. Exercise can energise, but the activity can also distract you from unwanted or negative thoughts.

Take notice. Gardens are full of interesting detail: plants, pests, colour, texture, scent and sound. Gardening can also foster mindfulness: an awareness of oneself and being in the moment. Set yourself a specific target for your garden, the sense of achievement when you complete it can give you a real boost.

Learn something new. If gardening is all very alien to you why not visit the Royal Horticultural Society website at: <https://www.rhs.org.uk/> for some great tips to get you started. Learning and trying new things is a great way to stimulate your mind.

10 tips to keep your mind active

It's also really important to try and keep your mind active as well. Here are our 10 tips that will give your brain a workout and get your creative juices flowing!

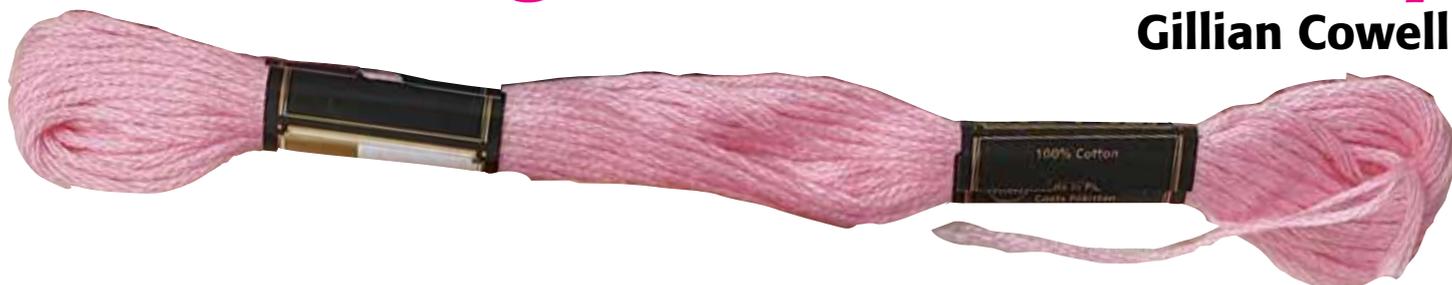
- ❖ Enjoy a daily puzzle or the crossword.
- ❖ Opt for mental arithmetic rather than use the calculator.
- ❖ Read more.
- ❖ Play mind-stretching games like bingo, bridge, chess or computer games.
- ❖ Start an online course.
- ❖ Bake a cake and get creative in the kitchen.
- ❖ Try writing. It could be a daily diary, your memoirs, or a short story.
- ❖ Stay in touch with friends and family. Remember to pick up the phone.
- ❖ Have a clear out or spring clean.
- ❖ Listen to podcasts or audio books.



We all have days when we feel life is getting on top of us. The 'every mind matters' website from the NHS is a great starting point to find support and guidance to look after your mental health: <https://www.nhs.uk/oneyou/every-mind-matters/>

Crafting with a colostomy

Gillian Cowell



As I write this (April 2020), we're still in the middle of a worldwide pandemic. Keeping my racing mind occupied is not easy, and I imagine I am in good company. A lot of us will already be coping with everything that a chronic medical condition brings: from physical pain, to trauma, anxiety, anger and depression, as well as the ways it challenges our identities and self-esteem. Add coronavirus fear, and perhaps even dealing with having the virus itself, and it seems that now more than ever we need arts and crafts to help us through and keep our hands and minds busy. Of course, throughout history arts and crafts have played a crucial role in helping us cope with adversity.

A BBC survey of nearly 50,000 people found that in difficult times, creative practice can be really helpful in distracting us. It increases our self-esteem and inner strength, gives us the space for our minds to contemplate our problems and emotions and process them in a controlled way. In other words, crafting can help us regulate our emotions, and distract us from difficult thoughts, experiences and memories. It can also help us to work through problems more calmly than without the craft as the intermediary. And excitingly there is also apparently a cumulative benefit in regular crafting activity.

The academic Susan Luckman explains that the repetition within crafts like crochet, knitting, weaving, needlework, woodwork and ceramics allows us to enter a 'flow state', which is the ideal state between concentration and action where the world melts away.

Important research is being done to evaluate the concrete effects of arts and crafts on our wellbeing. Oxford University runs the Yarnfulness Project to explore the potential connection between yarn crafts and mindfulness. Also, in 2017 the UK Parliament's All Parliamentary Group on Arts, Health and Wellbeing carried out a major Inquiry into practice and research

involving the arts in health and wellbeing, with over 300 people from around the UK participating. The Inquiry found that engaging with the arts can '...tackle chronic distress; enable self-expression and empowerment and help overcome social isolation', amongst other major positives. Many of you may have benefited from occupational therapy involving crafting, art psychotherapy or attended a local arts therapy group.

The Craft Council states that crafting can ease anxiety, depression, loneliness and dementia. They cite a research study by University College London, which found that 'Cultural activities encourage movement, reduce social isolation, and lower inflammation and stress hormones such as cortisol.' The study goes on to explain that the arts are connected with dopamine release, which stimulates cognitive flexibility. For me, making something during difficult times can help me focus on something positive, and if I've had a bad day I have still accomplished something that lifts my spirits.

Crafting also gives a bit of distance from whatever is happening; when we

concentrate on making, our brains slow down enough to allow for a working through of grief, sorrow and loss. Community artist Clare Hunter talks about the '...mesmeric immersion in craft as a relief from inner turmoil', and how she turns to crafting in times of anxiety and grief. Whilst sitting with her dying mother she found that embroidery was a way to mourn through 'stitching down her sorrow'. Many of us are mourning something, whether it is the death of a loved one, the loss of our health, or something else. Last year I learned to crochet as a way to cope with the loss of my mother, who was a talented crocheter. It helped me to work through my feelings as I learned the craft she was passionate about.

Colostomy UK itself offers access to arts sessions through the Creative Minds project for local Stoma Support Groups. Further, I was so pleased to see that two other contributors to this issue mention crafts they engage in. Rachel Carthy talks about being part of a local arts committee and enjoys cross stitch, card making and découpage, along with live music and theatre. Jackie discusses the importance of





Author's embroidery of a 'perfect' digestive system (unfinished)

art therapy in her life, helping her to work through her trauma through art, specifically her stoma journey. Art therapy allows the participant to express themselves through the process of arts and crafts – the thing we make becoming a tangible piece that represents our pain, and part of the overall therapeutic process. Using art materials we can create images or objects that allow us to communicate what we are feeling, providing new and surprising perspectives on the issues affecting us. To find an Art Therapist near you, the British Association of Art Therapists (BAAT) has a searchable database. Visit: www.baat.org

There are so many arts and crafts out there: embroidery, crochet, knitting, punch needle, textiles, painting, drawing, paper arts, printmaking and sculpture, photography, woodwork, pottery, jewellery making, calligraphy and computerised art, to name just a few. These have numerous arts and crafts within them, so the list is endless. No doubt many reading this will be avid crafters too and find great solace and pride in what you make – not to mention the joy and awe you bring to friends and family. Working within limitations we may

have, the jeweller Marilyn Long has written a really useful article containing practical tips on how to adapt your crafting activities when you have a physical health issue: <https://blog.folksy.com/2018/09/27/how-to-craft-with-health-issues>

For many crafts you don't need to buy any specialist equipment or supplies: you can learn finger knitting, and make yarn from strips of an old t-shirt, by ripping up an old jumper, or with kitchen string or ribbon! Newspapers, magazines and old cards are perfect for collage. Given the current pressures on couriers and our postmen and women, and our environment, it's always good to see what we have at home that we might be able to use: paper, coloured pens and pencils, old paint samples, kitchen string, old fabric for quilting and for cutting up and making into something else. Clothes can be updated by embroidering interesting patterns or embellishing with patches and trims.

The MARCH Network, one of eight national research networks focusing on the arts and mental health, has compiled a list of creative activities you can get involved with in these times of social distancing,

self-isolation and shielding. They include online concerts, cross stitch, museum archives, origami, knitting, puppet-making, book clubs, mindful crochet, the Social Distancing Festival and the Stay at Home Literary Festival. You can view their ever-increasing list of activities via: www.marchnetwork.org/creative-isolation

You can craft in a group or learn a new skill without even having to leave the house, particularly with the endless tutorials on YouTube and elsewhere. I learned to crochet via YouTube, and I always turn to sites like Love Crafts (which has a great new craft podcast on YouTube), Etsy and Ravelry for patterns and inspiration. The Craft Council provides useful guides on joining a local craft group or setting one up yourself, which can reduce our sense of isolation and loneliness. They also have a sizeable range of downloadable resources on different crafts, and quite a few online classes (mostly accredited). Other useful online crafting repositories include Craft As Therapy on Instagram and the online learning portal Creativebug, where for a small monthly charge you have access to a huge collection of video tutorials and downloadable patterns for a wide variety of different crafts. Lastly, Hobbycraft has a great selection of tutorials on their blog, including inspirational ideas for papercutting, quilting, macramé, wall hangings, notebooks, jewellery, chocolates...the list is endless, see: www.hobbycraft.co.uk/ideas

Books I use regularly on crafting and mindfulness include *The Mindful Maker* by Clare Youngs and *Mindful Crochet* by Emma Leith. Clare's book contains 35 projects "to focus the mind and soothe the soul". Emma argues that learning something new through crafting can provide a sense of accomplishment and self-fulfilment, the familiarity with a pattern helping you to observe your thoughts and feelings as you work, and the distractions of soft feathery yarn from pain or anxiety. Further, Emma talks about the crucial role crochet has on her life in the introduction to her book: "It is the doorway to my happy place where pain and anxiety are softened and a state of peaceful acceptance resides. Crochet kept me grounded when the cancer diagnosis spun my world off its axis and it continues to help me with my pain on a daily basis. It doesn't make the bad stuff go away, but it can help transform it."

I hope that this short article has provided some inspiration, and as I crochet I will be doing so alongside a much bigger invisible network of fellow **Colostomy UK** members and supporters crafting in solidarity. ■



Colostomy UK: focus on fundraising



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

Supporting Colostomy UK

Colostomy UK is a self-funding charity that relies on donations and grants to fund all our activities. Every £1 that you donate really helps. There are loads of ways that you can support Colostomy UK. This issue we're going to focus on how you can do this through Facebook.

Fundraising through Facebook

Colostomy UK

Looking for an easy way to fundraise?
Why not set up a Facebook birthday fundraiser?

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

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

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

Through our Private Facebook group and Facebook page **Colostomy UK** currently supports and provides news and information to over 10,000 ostomates, their family members and healthcare professionals. But you might not be aware that Facebook is also a really straightforward and simple way for people to give back to us as well.

You can now make a donation to **Colostomy UK** by visiting <https://www.facebook.com/colostomyuk/> and clicking on the donate button.

You can now also set up a fundraiser as well. Just go to <https://www.facebook.com/fund/colostomyuk/> and follow the instructions.

As we've said elsewhere in these pages a fundraiser doesn't need to be a huge event like climbing Ben Nevis. One of the great options that Facebook offers is setting up a birthday fundraiser. It's free of charge and every pound donated goes straight to **Colostomy UK**.

Thank you!

Due to limited space we don't have room to thank everyone who has donated to or raised funds for **Colostomy UK** since the last issue, but we would like to highlight just a few of the fabulous people whose support we appreciate so much.

Barbara Harrison, Janey Jane, Lar Rufus, Graham Wells, Rachel Lyons, and Trish Nicholson are just some of those who have set up birthday fundraisers.



Karen McGuiness ran the Weymouth Bay 10K and has so far raised over **£320**.



Lynda Newell walked the entire 135km length of Hadrian's Wall.

Cubby Stephenson is planning to cycle from John o'Groats to Lands End. You can support him and read his story at this link www.justgiving.com/Cubby-Stephenson

Easy Fundraising

Easy fundraising is a website that allows you to donate to **Colostomy UK** at no extra cost to you while you shop with hundreds of the UK's top High-street brands.

All you need to do is:

- ❖ Register as a supporter on the Easy Fundraising website and
- ❖ Make sure that Colostomy UK (Colostomy Association) is added as your supported cause.
- ❖ You can then accumulate donations while you shop with any of their partner retailers.

For more information or to register just visit:

easyfundraising.org.uk/causes/colostomyassociation

Help us to make a difference

Doing something amazing is about the people that you help, not the challenge you take on. You don't need to climb Everest to fundraise for **Colostomy UK**. You can bake a cake, hold a tea party, or organise a sponsored walk.

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



Legacy

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

What your gift means

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

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

How to leave a legacy

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

Your solicitor will need the following information on our charity:

Name: **Colostomy UK**

Registered address: **Enterprise House
95 London Street
Reading
Berkshire
RG1 4QA**

Charity Commission registration number: **1113471**

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



Unity Lottery



Match **6** Digits

win £25,000 (plus a £2500 donation to us!)

Match **5** Digits

win £1,000

Match **4** Digits

win £25

Match **3** Digits

win entries into the next prize draw

Join **Colostomy UK's** Unity lottery and help improve the lives of ostomates throughout the UK. You'll be in with a chance to **win up to £25,000** each week while directly contributing to our cause! www.unitylottery.co.uk/causes/colostomy-uk/



The more you **Donate**
The more we can **Do**

To donate **£1**, text ColUK001 to **70201**

To donate **£5**, text ColUK001 to **70970**

To donate **£10**, text ColUK001 to **70191**

Help us **support** and **empower** people living with a stoma.

www.ColostomyUK.org/donate

0118 939 1537

Fundraising



amazonsmile

You shop. Amazon gives.

Step One

create an account:

smile.amazon.co.uk

search for Colostomy Association

Step Two

remember to go to:

smile.amazon.co.uk

and 0.5% of every order you place will go to us!

The more you
DO nate
the more we
can **DO**



Ways to donate

Online at:

www.ColostomyUK.org/donate/

www.justgiving.com/colostomyassociation/donate

Text giving:

To donate £1, text **ColUK001** to **70201**

To donate £5, text **ColUK001** to **70970**

To donate £10, text **ColUK001** to **70191**

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

My Details: Title: _____ Forename: _____ Surname: _____
 Home address: _____
 Postcode: _____
 Telephone (home): _____ Mobile: _____
 Email: _____

Date of Birth: _____ Month and year of operation: _____
 Reason for your stoma: _____ Stoma type: Colostomy Ileostomy Urostomy

Tick as appropriate: I would like to be kept informed by: Post Email Telephone. **Please tick if you would like a receipt**
 I would like to receive information about: Tidings magazine Bag and product manufacturers Colostomy UK, the work it does, including training, conferences, volunteer opportunities and fundraising.

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

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

I would like to make a donation of:
 £20 £30 or whatever you are able to give £ _____
 I enclose a cheque or postal order made payable to **Colostomy UK**
 Please debit my Visa/Mastercard/Maestro Card with the amount specified
 Card number _____ (Maestro only)
 Expiry date _____ Security code _____ (Maestro only) Start date _____ (Maestro only) Issue No. _____
 Signed _____ Date _____

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.
 Signature: _____ Date: ____ / ____ / 2020

I would like to make a **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 £20 £30 or other amount (please state) £ _____
 monthly quarterly annually starting on the 1st 15th 25th of month: _____ year: _____
 thereafter until further notice. (Please cancel any previous standing order in favour of this beneficiary).
 *Please allow one month's notice to ensure donation processes through banking system and state your donation amount in words: _____
 Please pay: NatWest Bank, Market Place, Reading, Berkshire, RG1 2EP
 Account name: **C.A. Ltd** Account No: **88781909** Sort code: **60-17-21**
 Name: (IN CAPITALS) _____
 Signature: _____ Date: ____ / ____ / 2020

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



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

Registered Charity No: 1113471



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

Harrogate Stoma Support Group

Earlier this year the group enjoyed their first chair yoga session. This was arranged through Colostomy UK and delivered by Lisa, one of the qualified trainers we use. Giovanni our Fundraising and Development Manager was thrilled to receive the following feedback:

Hi Giovanni

I just wanted to say thanks for organising Lisa to attend our quarterly stoma group in Harrogate to give our members a taste of chair yoga.

I was sceptical as to whether our members would enjoy the session and, as it was our first meeting of the year, I was unsure as to the numbers that would attend. However, I need not have worried!

When Lisa arrived, we set the room into a circle of chairs allowing room for members to be able to move.

The session was aimed at all abilities and everyone enjoyed it and managed to benefit in some way. She explained how each move would help if practised on a regular basis. Lisa made sure that she offered alternative positions for those that may struggle. She explained the benefits of each pose and additional moves that could be done at home. The relaxation/meditation proved to be a highlight, with many members commenting on how they felt this may benefit them in the future and would take it into their daily life.

Thanks again.

*Fiona Holtham
Salts Community Stoma Nurse*

If you want to find out more about the Harrogate Stoma Support Group, then please contact Gill Wilson or Fiona Holtham on: **01423 555 786**.

WAMS (Windsor, Ascot, Maidenhead and Slough Stoma Support Group)

WAMS recently celebrated its first anniversary.

It doesn't feel like it has been a year already, but here we are! All of you who were at our first meeting in March last year will remember how shy we all were, it was so hard to get a few words from anyone, and now...well, the last meeting was proof of how much more comfortable we all feel talking to each other about pretty much anything. It's so wonderful to see – here goes a cheer for the next 12 months!

Thinking back, we were surprised to see how much we did in our first year. We had a couple of sessions of chair yoga, we did some meditation, we had talks on travelling with a stoma, nutrition and hernias, we went swimming, we had an art session and produced some amazing paintings as a result and, in between all of that, we fitted our December WAMS party where we all enjoyed lots of food and prizes and raised £77 for our group. None of this would have been possible if it wasn't for our members – so thank you to everyone!

We also want to say thank you to Giovanni and **Colostomy UK** for helping us with the creation and running of the group as well as the sponsoring of some of our activities such as chair yoga and swimming which we couldn't have done without. And a special thank you goes to Liz Harris, our stoma nurse at Wexham Park Hospital, for coming up with the idea of having a local support group and making it a reality.

From all on the WAMS Stoma Support Committee

If you are interested in joining WAMS then please e-mail: wamsstoma@gmail.com or call: **0118 939 1537**.



EBOC (East Berks Ostomy Club)

I run the East Berkshire Ostomy Club in Bracknell, Berkshire.

We are a lively group of members and their partners who meet every Monday afternoon at our local community centre.

Once the information about the coronavirus started to circulate, we made it a point to discuss the matter with everyone. It was so nice to know that our members wanted to stay in touch whatever happened. Shortly after our last meeting (in which we planned what we would do if we were unable to meet together) the council, who run the community centre, contacted me to say that the centre was closing immediately and that no more meetings would be allowed until the virus threat was over.

We are now 'meeting' and talking to each other through e-mails. The first e-mail I sent to everyone had a message from **Colostomy UK** about support from them – with details of their 24-hour helpline and other contact details. This meant that everyone knew where to get support and advice if they needed it.

Now on a Monday, I contact the members by e-mail, and ask them how they are, ask for any light-hearted comments and any problems they may have. Once I have these, I compose a newsletter.

In the newsletter, which includes their comments, I tell them snippets of important colostomy news, and ensure that they are aware of all the advice coming in from all sources about how to recognise the symptoms of the coronavirus. If I feel they would benefit by reading items from voluntary council associations I add these too. I have also been adding some of the news from other contacts about how they are coping in their various situations – some are funny, some serious but most have very uplifting stories about the kindness of friends and neighbours. At this difficult time, I want every member to know they are not forgotten.

To find out more about East Berks Ostomy Group contact Jackie Dudley: **01344 426 652**.

BOTS (Bums on Tums) support group, Shropshire

Back in February members of BOTS enjoyed a Creative Arts session, which they organised through Colostomy UK. Irene Constable reported back as follows:

Hi Giovanni

Here are the pictures (above and below) from our art day on Thursday. As you can see there were about 20 members there and I have shown each of their works of art. Some brilliant and others (mine included) not so brilliant. We can't all be artistic though can we? There was much laughter all afternoon, so I know everyone had a fabulous time. They want to do it again, perhaps later in the year and you kindly said that Colostomy UK would fund another session for which we are very grateful. Perhaps November? Once again thank you Colostomy UK for arranging this wonderful afternoon for us.



Looking for online support?

Our private facebook group is a secure and supportive community of over 8,000 people where you can find support from others with a stoma, offer advice and, if you need it, just find someone else to talk to. It's not just for those with a stoma; friends and family are welcome too. Search for 'Colostomy UK support group' on Facebook and request to join.

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

www.ColostomyUK.org



Stoma care open days

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

Colostomy UK volunteers, all of whom either have or have had a stoma, attend stoma care Open Days all over the country whenever possible. Do come along, call at our stand and have a chat.

Open Days that we are aware of at the time of going to press are listed below. An up to date list, including events in your area, can be viewed on the **Colostomy UK** website.

At the time of going to press we had the following open days still listed as going ahead. However, given the ever-changing situation with regards to the coronavirus, we strongly advise you to contact the organiser before attending.

Coloplast Event

Winstanley House Hotel, Braunston, Hinckley Road, Leicestershire
 4 June 2020 10:30–14:00
 Coloplast: 0800 220 622

Coloplast Event

Old Alresford Place, Alresford, Hampshire
 9 June 2020 10:30–14:00
 Terry Anne Horncastle: gbtah@coloplast.com or 07770 494 727 or Julie: gbjtu@coloplast.com or 07469 144 186

Coloplast Event

Kettering Park Hotel, Kettering, Northants
 18 June 2020 10:30–14:00
 Coloplast: 0800 220 622

Coloplast Event

Marwell Zoo, Thompsons Lane, Colden Common, Winchester, SO21 1JH
 1 July 2020 10:30–14:30
 Terry Anne Horncastle: gbtah@coloplast.com or 07770 494 727 or Julie: gbjtu@coloplast.com or 07469 144 186

Oxford University Hospital

Patients Open Day
 Tingewick Hall, John Radcliffe Hospital, Oxford, OX3 9DU
 11 July 2020 10:00–13:00
 Contact: Stoma Care Department



To get your open day added to our website and included in *Tidings* please e-mail: info@ColostomyUK.org or call our admin line **0118 939 1537**.

National support organisations

IA The Ileostomy and Internal Pouch Support Group

www.iasupport.org
 Telephone: 0800 0184 724
 e-mail: info@iasupport.org

UA Urostomy Association

www.urostomyassociation.org.uk
 Telephone: 01386 430 140
 e-mail: secretary@urostomyassociation.org.uk

Mitrofanoff Support

www.mitrofanoffsupport.org.uk
 Telephone: 07903 382 013
 e-mail: info@mitrofanoffsupport.org.uk

Purple Wings

www.purplewingscharity.com
 e-mail: lauren@purplewingscharity.com

IOA International Ostomy Association

www.ostomyinternational.org

Junior Ostomy Support Helpline (JOSH)

via the Colostomy UK 24-hour free helpline: 0800 328 4257
 e-mail: info@ColostomyUK.org

Breakaway Foundation

www.breakawayfoundation.org.uk
 Telephone: 01283 240 253
 e-mail: info@breakawayfoundation.org.uk

Bowel Cancer UK

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

Macmillan Cancer Support

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

Crohn's and Colitis UK

www.crohnsandcolitis.org.uk
 Telephone: 0300 222 5700
 e-mail: info@crohnsandcolitis.org.uk

The IBS Network

www.theibsnetwork.org
 Telephone: 0114 272 3253
 e-mail: info@theibsnetwork.org

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

If, you are thinking of starting a support group in your local area, or are perhaps about to take over the running of an existing one, then please don't hesitate to get in touch with us for advice,
Tel: 0118 939 1537 or e-mail: info@ColostomyUK.org

Stoma support groups in your county

Channel Islands

Guernsey

Guernsey Ostomates
Luci Deane 01481 236 077 /
lucideane58@gmail.com

Jersey

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

England

Berkshire

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

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

WAMS (Windsor, Ascot, Maidenhead &
Slough) Stoma Support Group
If you are interested in joining then
please e-mail wamsstoma@gmail.com
or call 0118 939 1537

Bristol

Bristol Ostomy Self Support (BOSS)
Janet on 01934 248 114 or Rob on
0117 966 8021

Buckinghamshire

High Wycombe Stoma Support Group
Tel: 0800 318 965

Milton Keynes Stoma Support Group
(MKSSG)
Morag Harvey (Secretary) mkssg.sec@gmail.com 07843 768 386

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

Cambridgeshire

Peterborough Stoma Support Group -
Ostomistics
Alan Wright 01354 653 290 / 07836
661 102 <http://www.ostomistics.org/>

Cheshire

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

Crewe & District South Cheshire Stoma
Group

Mrs Joan Owen, 01270 764075 email:
joan.o@btinternet.com

Stockport Support Group

Marion Caulfield: 0161 320 9400 /
0800 652 6667

Warrington Ostomy Support Group
Louise or Joan on 01925 454 813

Cleveland

Oops Group

Julie Morrisroe/Carol Younger/Alison
Hall-O'Donnel: 01287 284 113

Co. Durham

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

Darlington Support Group

Margaret Clothier, Tel: 0191 333 2184

Durham Stoma Support Group
Lynn Ridley, Tel: 0191 333 2184

Cornwall

Cornwall & Plymouth Bowel Cancer
Support Group

The Secretary: 01872 241 145,
cbcsinfo@gmail.com or website www.cornwall-bowel-cancer-support-group.co.uk

Cornwall Ostomy Support

Ken Jones: 01872 863 106 or www.cornwallostomysupport.org.uk

Lanhydrock Ostomist Group

Mandy Rowe: 01726 832 642
E: murphy.rowe781@btoopenworld.com;
Henry Kendall: 01208 850 986
E: h.kendall380@btinternet.com

Cumbria

Grange Cancer Support Drop in
Marie O'Connor 01539 533 279

Stoma Support Groups in North
Cumbria

Stoma Care Nurses 01228 814 179

Derbyshire

Diverted Local Stoma Support Group
Diana Manning: 01283 541 311

F.I.S.H.Y.S. (Friendship, Information,
Support & Help for Young Ostomates
(age 18-45)

Email: fishysderbyshire@gmail.com

Mercia Inside Out Stoma Support
Group

Sally Chester 07500 441 442; Jackie
07919 002 612; Gary 07779 218 245

Devon

Devon IA

email: devon@iasupport.org

Mid Devon Ostomy Support Group

Janice - janice234ford@gmail.com or
tel: 07923 975 051 or 01884 799 369

Plymouth & District Bowel Cancer
Support Group

Wendy Wilson - Facebook: Plymouth
Bowel Cancer

Dorset

Colostomy Urostomy Pouch Ileostomy
of Dorset - CUPID (Bournemouth)

Beryl Andrews 01202 483 303

Colostomy Urostomy Pouch Ileostomy
of Dorset - CUPID (Poole)

Jenny Pipe: 01202 740 440

Colostomy, Urostomy, Pouch &
Ileostomy of Dorset - CUPID (West
Dorset)

Colin Clare - 01305 853 238

Essex

Connect

Lin Hart 01279 505 273
email: comeconnectwithus@gmail.com

Mid Essex Stoma Support Group

Paul Foulger: 01245 224 374

N.E.S.S (North Essex Stoma Support)

Brian Waller - 01206 540 449

Optimistic Ostomates

Angela Taylor 01702 385 510

Redbridge Ostomists Club

Stoma Nurses

Chris/Lisa: 020 8970 8321

STEPS - Stoma Essex Patients Support

01268 451 937 or

email- stepsessex@gmail.com



Hampshire

Replummed stoma support group
www.replummed.me
Solent Ostomates Support Group
(S.O.S.)
For information tel. 07527 707 069 or
solentostomates@hotmail.co.uk
Southern Ostomy Group
Caroline or Karen on: 07756 819 291
southernostomygroup@hotmail.com
The Hampshire Ostomates Support
Group
Contact Nicki Beare on 07771 558 458
or email:
Hampshireostomatesgroup@gmail.com
Waterside Stoma Support Group
Hazel Derham: 023 8089 1934 or
hayjuder@sky.com
Wessex Urology Support Group
Mrs Jo Stacey: 07910 786 978

Herefordshire

Herefordshire Stoma Support Group
Carol Steele 01432 880 656 or
email: carolsteeleglo@gmail.com

Hertfordshire

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

Isle of Man

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

Isle of Wight

Optimistics
CNS's Sarah Capon & Sarah Varma
01983 534 009

Kent

Ashford Stoma Support Group
Carole Hobbs: 01303 814 014
Atoms Support Group
Maria Culleton, SCN: 01227 769 679 or
07827 997 424
Dartford Ostomy Group Support
(DOGS)
Tracey or John: 07779 155 846 or
07948 974 350 or
dogs-uk@hotmail.com
Dover Stoma Friends Group Support
Julie Bell/Ros Marshall: 01233 616 646
and Support Group Organiser June
Golding: 01304 822 696
GOGS (Gravesend Ostomy Support
Group)
Tracey: 07779 155 846 or
Helen: 07710 780 958
M.O.G.S (Medway Ostomy Group
Support)
Tracey: 07779 155 846;
Helen: 07710 780 958 or
email mogs-uk@hotmail.co.uk
Maidstone Stoma Support Group
Judy/Kirsty: 01622 224 305
Sheppey Ostomy Group Support (SOGS)
Shelley 07714 734 194
sogs-uk@hotmail.com
SWANS Stoma Support Group - Swanley
Heather - 07711 445 312
heather601@virginmedia.com

Thanet Stoma Buddies Support Group
Kathy 01843 291 825
Tunbridge Wells Stoma Support Group
Cathy Chitty/Mags Donovan
01892 632 323

Lancashire

Kangaroo Klub, Blackpool stoma
support group
Stoma department
Tel: 01253 956 620 or e-mail crc-
stomanurses@bfwhospitals.nhs.uk
North Manchester and Bury Stoma
Support Group
Julie Meadows (SCN) 0161 720 2815 or
07774 263 563
Oldham Stoma Support
June Wilde: 0161 312 5538

Phoenix Bowel Cancer Support Group
Sandra Peet: 01772 683 790,
www.phoenixgroupbvh.com or
eMail: sandrapeet7@aol.com

Leicestershire

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

Lincolnshire

Grantham Support Group
Bobbie/Rachel: 01476 464 822

London

Bowel & other Cancer Support
Newham
020 8553 5366
Homerton Hospital Bowel & Stoma
Support Group
Angela Davy: 020 8510 5318 or
020 8510 7599
Newham Stoma support group
Contact Lauren King 020 7055 5576
Rectangle - Colorectal Cancer Support
Group
Regina Raymond 020 7472 6299
South Woodford Support Group
Nurse Christina and Lisa:
020 8535 6563
Surrey & South London Bowel Cancer
Support Group .
Sue Berry: 01737 553 134 or
John Amos: 020 8668 0796
Time 2 Talk
Ifrah Mohamed - 07463 838 718
mybodysauthor@gmail.com,
Viki Palmer - 07894 276 986

Merseyside

Bowel Cancer and Stoma Support
Group (BeCauSe Group)
Tel: 07948 120 955
I.C.U.P.S
Sue: 07742 237 013
St Helens Cancer Support Group
Denys Floyd- 01744 884 097

Middlesex

Inside Out
Bob (chairman): 020 8428 4242

Norfolk

James Paget Ostomy Support Group
Sandra Hutchings: 01502 585 955

Kings Lynn Ostomy Friendship Support
Group
Tel: 01553 775 698 / 01553 674 962 /
01553 768 271

Norfolk Ostomates Support Group (on
Facebook too)
Barbara Harris 01603 417 046 or
07789 581 312
STARS (SToma And Reconstructive
Surgery social support group)
Sylvia Hughes 01263 733 448
sylvia.ruth.hughes@gmail.com

Northamptonshire

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

Northumberland

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

Nottinghamshire

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

Shropshire

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

Somerset

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

Staffordshire

County Stoma Group
Moira Hammond 07788 402 195 /
cm.hammond@ntlworld.com
Outlook The North Staffs Ostomy
Support Group
Moira Hammond 07788 402 195 or
e-mail: cm.hammond@ntlworld.com

Suffolk

East Suffolk Ostomy Group
Marion Fisher: 01473 311 204
James Paget Ostomy Support Group
Sandra Hutchings: 0150 258 5955
West Suffolk & District Stoma Group
Jessica Pitt stoma nurse:
01638 515 525

Surrey

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

SUPPORT

Sussex

Brighton & District Support after Stomas (SAS)

Virginia Keefe: 01273 723775

Chichester Stoma support Group

The Stoma Care Team 01243 831 527

The Ostomy Friends Group

Jane Quigley: 01323 417 400 ext 4552

West Sussex Princess Royal Stoma Support

Tina Walker: 01444 441 881 ext 8318

Tyne and Wear

Gateshead Stoma Patient and Carer Support Group

Stoma Care Nurses: 0191 445 3152 or email stuart.sutcliffe81@yahoo.com

NHS Molineux Support Group

John Burchell 0191 265 1047

Royal Victoria Infirmary Support Group
Stoma care nurse specialist:

0191 282 4116

South Tyneside Hospital and Community Stoma Support Group

Jayne Barnes, Teresa Liddle, Amanda Logan: stoma care nurses

Sunderland Support Group

Michele Downey 07704 949 30

email: micheledowney@outlook.com

Warwickshire

Warwickshire Stoma Support Group
nuneatonstoma@aol.com or

Bob: 07564 680 803

West Midlands

Birmingham, IA

Michael Jameson 0121 355 2745 / 07842 555 070 See also: <https://birmingham.iasupport.org/events>

Coventry Stoma Support

Martin - 07947 385 643

Wiltshire

Swindon IA

www.swindon-ia.org.uk

Wessex Stoma Support Group

Karen Barryman 01980 590 599 or 07799 863 766

Email: info@wessex-stoma.co.uk

Website: www.wessex-stoma.co.uk

Worcestershire

Kidderminster & District Collossus Support Group

Brendon Drew: 01299 400 843

Yorkshire

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

Airedale Stoma Support

Sue Hall: 01535 646 373

Barnsley Bottoms Up Stoma Support Group

Stoma Nurses 01226 432 528 or

Celia Utley (Chairman) 01226 284 262

Behind You (Calderdale & Huddersfield Bowel Cancer Support Group)

Stoma Care Nurses: 01484 355 062

Bottoms Up (for urology and colorectal cancer patients)

John Whelpton 07974 657 146 email: midyorks.bottomsup@gmail.com

Bradford Stoma Support Group

Lisa Hall 07552 276 747

Dewsbury & District Stoma Support Group

June 07884 003 945 or

email dews.ssg@gmx.com

Hambleton and Richmondshire Ostomy Support Group

Stoma Care Nurses - Judith Smith and Mary Hugil 01609 764 620 / 07736 295 131

Harrogate Stoma Support group

Stoma department office – Nurse Gill Wilson/Fiona Holtham 01423 555 786

Leeds Bowel Cancer Support Group

Lynda Castle (Colorectal Nurse Specialist) 0113 206 5535

Scarborough Stoma Support Group

Stoma Care Team: 01723 342 388

The Hull and East Riding Colostomy Support Group

Pete Smith: 07989 565 335 or

Pete Rennard: 07939 518 642 /

01482 793 966 www.hercosg.org.uk

Northern Ireland

County Antrim

Belfast City Hospital Stoma Nurses

Audrey Steele, Karen Boyd, Kirsty Niblock, Annette Lambert, Emma Dunn tel 028 9504 5941

Colostomy UK Volunteers Northern Ireland

Chris Wright: 07720 717 771

County Armagh

Craigavon Area Hospital

Claire Young/ Lynn Berry/ Tanya Garvie 028 3756 1845 (Direct Line)

Daisy Hill Hospital Support Group

Bernie Trainor: 028 3756 2932 (Direct Line)

County Down

North Down Stoma Support Group

Adrian Ewing on 07850 741 511

Ulster Hospital

Hazel/Martina: 028 9055 0498

Londonderry

Causeway Support Group

Mary Kane: 028 7034 6264

Republic Of Ireland

County Mayo

Mayo Stoma Support

Marion Martyn: +353 94 902 1733

Dublin

Bowel Cancer Support Group (ICS)

Dublin

National Cancer Helpline:

+353 1 800 200 700 or

Olwyn Ryan: +353 1 231 0500

Scotland

Ayrshire

Ayrshire & Arran Stoma Support Group

Hugh Strathearn 07837 464 376

Email: hstrath@aol.com

Stoma Care And Recovery (SCAR)

Maggie: 01294 271 060/ 0781 773

6147 maggie13@sky.com or

Rhona: 01294 557 478

Fife

Fife Ostomy Support Group

Ishbel Barr: 01592 772 200

Lanarkshire

Glasgow Stoma Support group

Morag Sinclair 0141 779 1322 or

Jackie McChesney 01505 324 052

Moray

Moray Ostomates Support Group

Meggie 01343 552 449 /

Kathleen 07789 684 285

Scottish Borders

Stoma Support Group

Nancy Fraser: nancyfraser@talktalk.net

or 01450 374 012. Fiona Gentleman:

r.gentleman@sky.com or

01450 371 063

West Lothian

Bring Your Own Bag Stoma Support Group

Western General Stoma Team

0131 537 1000

GOSH (West Lothian)

Scott Pattison: 07502 163 644

Wales

Aberystwyth

West Wales Stoma Support Group

Shirley Jones:

westwalesstomagroup@gmail.com

Bridgend

Bridgend Ostomy Patients Support Group

bridgend.ostomy@gmail.com

Carmarthenshire

W.O.W.S. Wales Ostomy West Support

Judi Hopkins 01267 237 847 or

Julian Boswell 01554 772 877

Conwy

North Wales Ostomy Support Group

Hazel - 07976 817 246 or

Lesley - 07828 837 325

Gwent

Blaenau Gwent Self Help

Celia McKelvie: 01873 852 672

After 6pm

Cwmbran Ostomy Support Group

(COSG)

Philippa Lewis: 01633 791 339 /

07504 713 069

Mid Glamorgan

C.A.S.S Colorectal and Stoma Support Group

Chair person 01685 877 144

Pembrokeshire

PSA (Pembrokeshire Stoma Association)

Rosemarie Rees Paton: 01437 532 473

Powys

The Bracken Trust Cancer Support Centre

Helen Davies: 01597 823 646

Rhondda Cynon Taf

Royal Glamorgan Stoma Care Support Group

Domonica Lear 01443 443 053

Swansea

Swansea Ostomy Self Help Group

Glynis Jenkins: 01792 418 245

Colostomy UK literature range

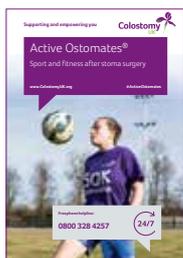
Have you seen our extensive range of support literature? Suitable for ostomates, family members, friends, carers and healthcare professionals.

To order your complimentary copies contact us by:

adminline:
0118 939 1537

eMail:
info@ColostomyUK.org

website:
ColostomyUK.org/information



Active Ostomates
Sport and Fitness
after stoma surgery



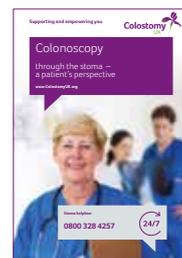
Campaigns &
Projects Flyer



Caring for
Colostomates



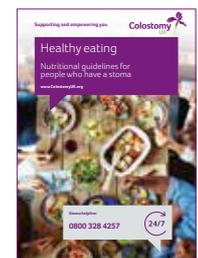
Caring for a person
with a stoma and
dementia



Colonoscopy
through the
stoma



Fundraising
Pack



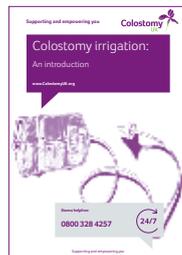
Healthy Eating



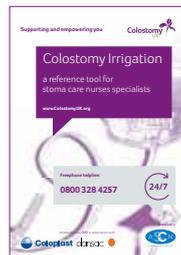
Helpline Cards



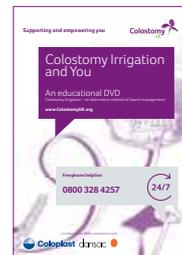
How will a
Colostomy
affect me?



Irrigation
Booklet



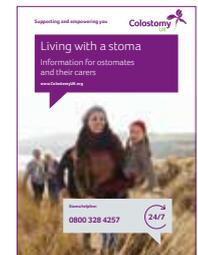
Irrigation DVD
(nurses)



Irrigation DVD
(patients)



Legacy Flyer



Living with
a stoma



One to One
(join us) Flyer



Ovarian
Cancer and
stomas



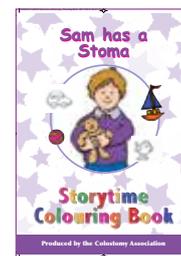
Pain &
Discomfort



Parastomal
Hernias



Rectal
Discharge



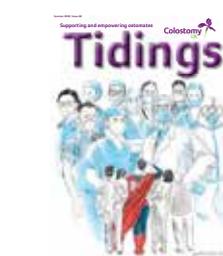
Sam has a stoma
(colouring book)



Stoma friendly
toilet guideline
and stickers



Stoma
Reversal



Tidings
Magazine



Travel Advice



Travel
Certificate



Tri-Charity
Leaflet



Welcome Pack

CUI - Committed to providing optimum support and excellent customer service

We develop, manufacture and provide bespoke hernia support garments, ostomy underwear and swimwear.

Ensuring that our garments offer comfort and security for your peace of mind and quality of life. Our dedicated team of Support Specialists offer personal consultations in the comfort of your own home, over the phone/video or in a clinic setting.

Please contact us to book your consultation by phone 0800 279 2050 or email: customersupport@cuiwear.com



Anti-roll wrap around support belt with glove design



Baby & Junior support belts



Seamless tube support belt



Wrap around adjustable hole support belt

