

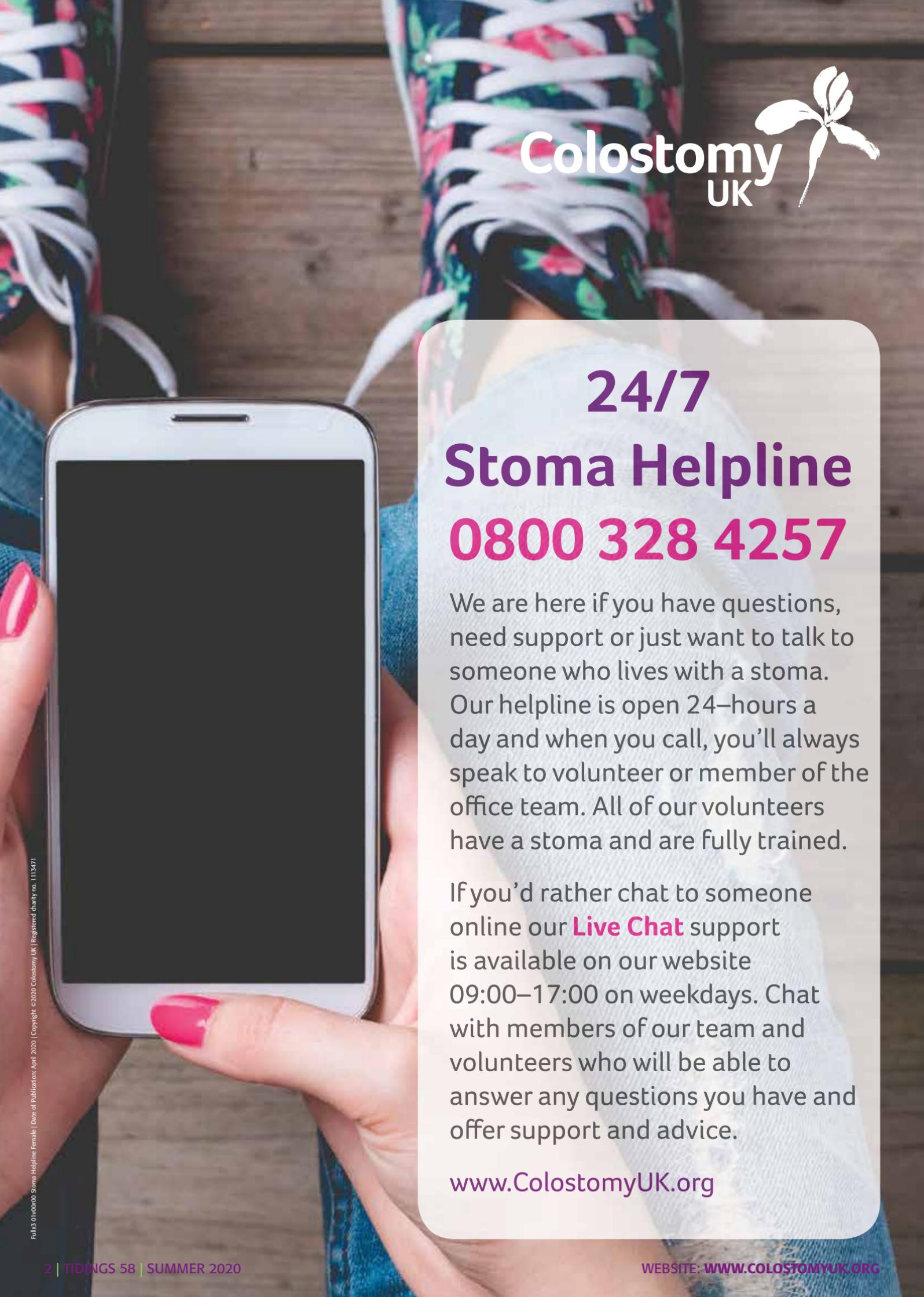
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Tidings



A fond farewell and thank you to our former editor



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www.ColostomyUK.org



Dear readers



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Senior Stoma Care Nurse Specialist

Ambra Bertinara

Colostomate & Volunteer

Jackie Dudley

Colostomate & Volunteer

Gillian Cowell

Data Analyst & Publishing

Arvind Anand

**Your support has never mattered more!
And we want to say a BIG thank you to everyone
that has supported us during these times.**



I hope that by the time you read this you will have had the chance of a break or a 'staycation' as the Prime Minister recently advocated. Like many others, I have found the months since March challenging. Although much of my adult life has been spent working from home, it is the restrictions on daily activities I have found the most difficult. It seems though, that things are now heading in the right direction. As I write this at the end of July, we are starting to plan for a gradual return of the team to the **Colostomy UK** offices. One thing this will mean, is a quicker turnaround of requests for things like RADAR keys and our literature. Thank you to everyone for being patient with us up to now!

My happiness at the general easing of lockdown restrictions across the UK is however dulled slightly by anxiety over whether we are going too fast; a feeling I am sure I share with many readers! There is one aspect of this easing though, that can only be good news: the 'restart' of business as normal in the NHS. Understandably, many ostomates experiencing problems have been putting off seeking medical help. The message from our president Ian Daniels, who is also a consultant colorectal surgeon, is that people should now be contacting their stoma care departments and GPs in the normal way. Indeed, when he spoke with our general manager the other day, he was very keen that we get this message across to readers, simply because leaving something untreated for too long often turns a small problem into something much bigger and more difficult to resolve. You can read more about what he said in Colostomy UK news (page 6).

I was thrilled to receive lots of positive feedback about the last edition of *Tidings*. The general feeling was that it managed to capture the strength and sense of togetherness present amongst the ostomate community. Hopefully, you will enjoy this edition just as much. Along with the usual features, it too contains a varied assortment of articles. Our 'Real Lives' stories cover everything from emergency stoma surgery to the impact that the coronavirus had on a world cruise. The Bowel Disease Research Foundation outline some new research they have helped fund into diverticular disease. There is the second part of our paediatric ostomy series from Canada. We also return to the issue of mental wellbeing and arts and crafts, learning how one ostomate used drawing and painting both to chart his stoma journey and help him through its difficult twists and turns. I will leave you to discover what else is on offer, but one piece I encourage you to read, is Jackie Dudley's tribute to Rosemary Brierley, who recently retired from the *Tidings* editorial board. Rosemary has been involved with the magazine for many years, during which she has also completed two stints as editor. In the short time that I have been editor, her help and advice has been indispensable. We also had the privilege of going to the British Medical Association together last year to receive an award for *Tidings*. So I will end by asking you all to raise a virtual glass to Rosemary (pictured on the front cover): Cheers!!



Richard

Richard Biddle
Editor,
Writer & Researcher

Tidings Magazine:

The views expressed by the contributors are not necessarily those of Colostomy UK. Great care has been taken to ensure accuracy, but Colostomy UK cannot accept responsibility for errors or omissions.

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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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experience based advice and
guidance from a volunteer.

0800 328 4257

24 hours a day and completely free.

Adminline for:

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

0118 939 1537

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

info@ColostomyUK.org

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

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info@ColostomyUK.org

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rates: **0118 918 0500**

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Social media:



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 49 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



Libby Herbert
General Manager
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Colostomy UK Team

Since the last edition of *Tidings*, the **Colostomy UK** team has continued to work from their homes, linking up via e-mail, telephone and Zoom. This included the *Tidings* editorial meeting for the edition you are currently reading! From May onwards we have made periodic visits to the office, in order to collect and respond to post and send out orders for our literature etc. Thank you to everyone for your support and understanding. At the time of going to print, we are preparing for a gradual return to our offices, which we hope will happen in early August.

Documentary by Emma Snow

Earlier in the year we were approached by freelance BBC journalist Emma Snow and asked to take part in and support a short documentary she was producing called 'Extra baggage: Living with a stoma'. This followed the lives of three young people coming to terms with stoma surgery. It's had some great feedback already. If you haven't seen the documentary, then you can watch it online: https://www.youtube.com/watch?v=RQ9GIHG4k_Q

Important Notice to Ostomates

The news that the NHS is restarting routine work (including surgery) is obviously very welcome. We know that while the country has been in lockdown, people have held off seeking treatment and advice for medical issues, as they wanted NHS resources to be focused on those with Covid-19. The message from our president Ian Daniels FRCS, consultant colorectal and general surgeon, is that people should now contact their stoma care departments and GPs in the normal way. As he explained when he spoke to Libby, our general manager, delaying seeking help can lead to a small problem becoming much bigger and more difficult to treat. Ambra Bertinara (who is a member of the *Tidings* editorial board and also a senior stoma care nurse specialist) echoed Ian's message, adding that patients should contact their stoma department or GP by phone. She explained that telephone consultations were the initial course of action, so as to limit the number of people visiting hospitals and GP surgeries. However, depending on the issue and clinical judgement, a face-to-face consultation might be arranged.

In summary: if you have a medical issue, then you should not hold off from PHONING your GP or stoma care team.

Colostomy UK Website

Visitors to our website will know that we have a page dedicated to Covid-19. We will continue to update this with information relevant to ostomates, until further notice.

Fittleworth Podcast



fittleworth

We were delighted to be invited to take part in Fittleworth's 'In Good Company' podcast with Carrie Grant, along with our volunteer Bobbie Minshull, our Mindfulness and Meditation tutor, Sophie Mills and a representative from the charity 'Independent Age'.

The podcast explored activities and steps people who are feeling isolated could take in order to reconnect with others. This was of course very topical with many people having to cope alone with the current restrictions on meeting others. We were able to talk about our Active Ostomates® initiative, focusing on 'home' activities and the positive impact these have had (and continue to have) on people. We also ran through the many ways in which **Colostomy UK** is able to support people, including our 24-hour Stoma Helpline and recently launched instant messaging service (available through our website). Bobbie spoke about her background to having stoma surgery and the positive effect that volunteering has had on her. If you would like to listen to the podcast then visit: <https://www.fittleworth.com/ingoodcompany/>

British Toilet Consortium

Thanks to our membership of the British Toilet Consortium, we were able to work with other charities to push central government to produce guidance for the reopening of public toilets by local authorities, as Covid-19 lockdown restrictions are gradually eased.

Some positive news came in early July, when the Ministry of Housing, Communities and Local Government, and the Department for Environment, Food and Rural Affairs, published guidance acknowledging at the same time that 'closed toilets may also impact disproportionately on certain groups who rely on access to public toilets to be able to leave their homes'.



Nicola Ridler

We were very sad to learn of the passing of Nicola Ridler, after a long fight with stage four bowel cancer.

Nicola had the spirit of a lion: courageous and strong. She told her story in the winter 2019 edition of *Tidings* and was a staunch and active supporter of **Colostomy UK**. She frequently took to social media, both to raise awareness of life with a stoma and to champion our work. Our thoughts are with her family.



New joiners to the Colostomy UK team

Fundraising trustee



Sarah Affleck

Sarah Affleck has been in north Hampshire for the last 15 years, married to Marcus with whom she has two boys, both at secondary school.

Sarah's career has always been in the charitable sector, a common thread being supporting people to live more independent lives. Starting as a support worker, Sarah went on to manage supported accommodation schemes, community outreach programmes and out-of-school clubs. Nearly seven years ago, Sarah moved into fundraising when she

began volunteering for her local branch of Samaritans. Providing fundraising support, Sarah also served four years as a trustee for the branch. Having fundraised across multiple income streams for several disability charities, Sarah now works for a national charity focusing on raising funds from charitable trusts, foundations and statutory sources. Sarah is a member of the Chartered Institute of Fundraising and holds a Diploma in Fundraising Practice.

Office and Finance Assistant

We are pleased to welcome Angela Jarvis to the Colostomy UK team.

Angela will be our office and finance assistant while Jo Hammond is on maternity leave (at the time of going to press, still no news on the baby!). Angela has a background in accountancy and has also been a volunteer with a number of different charities.



Angela Jarvis



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: volunteers



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

Volunteering during a pandemic

As Volunteers' Manager, it is heartening to see 'volunteering' playing such a key part in the response to the coronavirus pandemic. The NHS responders' service was set up with immense speed. I think everyone was amazed at the scale of response, but not by the desire that motivated it. When I recently asked our volunteers why they wanted to volunteer, the sentiment was to "give something back" and "to help others". I think this can be seen by the numbers of people who signed up and wanted to do something at a pivotal time.

From my point of view, I am hoping there will be much **Colostomy UK** can learn from the speed with which NHS responders were recruited and went 'live'. We may not have the same resources as the government and the NHS, but it will be useful to work out where we can improve and streamline our own systems going forward. Hopefully too, there will be many good practices we can 'borrow'!

I also wonder how the experience of the pandemic will affect the expectations of future volunteers? I know from media reports that some NHS responders have found they weren't as busy as they had hoped. This would have been disheartening for them, but also an indicator that people were managing well themselves or with community grassroots support, which galvanised at an even quicker pace. As we move forward, volunteers coming to **Colostomy UK** may have differing expectations from us and it is important we accommodate these while being realistic at the same time.

Our Volunteers

Some of our volunteers have experienced similar disappointments to NHS responders, for example those who represent us at open days and hospital events. For others, it has been pretty much business as usual, such as those who take calls on our 24-hour Stoma Helpline. Just like everyone else, our volunteers are 'normal' people too, and so some have been shielding and some will have felt the impact of lockdown on their wellbeing intensely. Hence, we have done our best to keep in touch with them, with regular newsletters and updates. This is something I know that many of the stoma support groups have been doing for their members and I think it's generally welcomed.

Whilst in lockdown, we have also used the time to try some new things.

We now have a small team of volunteers able to provide **telephone befriending support**. Social isolation and loneliness is not a new experience, but lockdown may have accentuated these feelings for many. Indeed, you will have probably seen in the media that there



Colostomy UK's very first 'virtual' coffee morning!

is growing evidence of this. But for new ostomates or perhaps ostomates living alone, it's possible that the feelings of isolation are even greater. This is where we hope to make a difference. Our team are ready to buddy up with any ostomate that feels they would benefit from a weekly check and chat call for up to 12 weeks.

We have also found ourselves connecting in new ways, most notably in 'Virtual' communications...

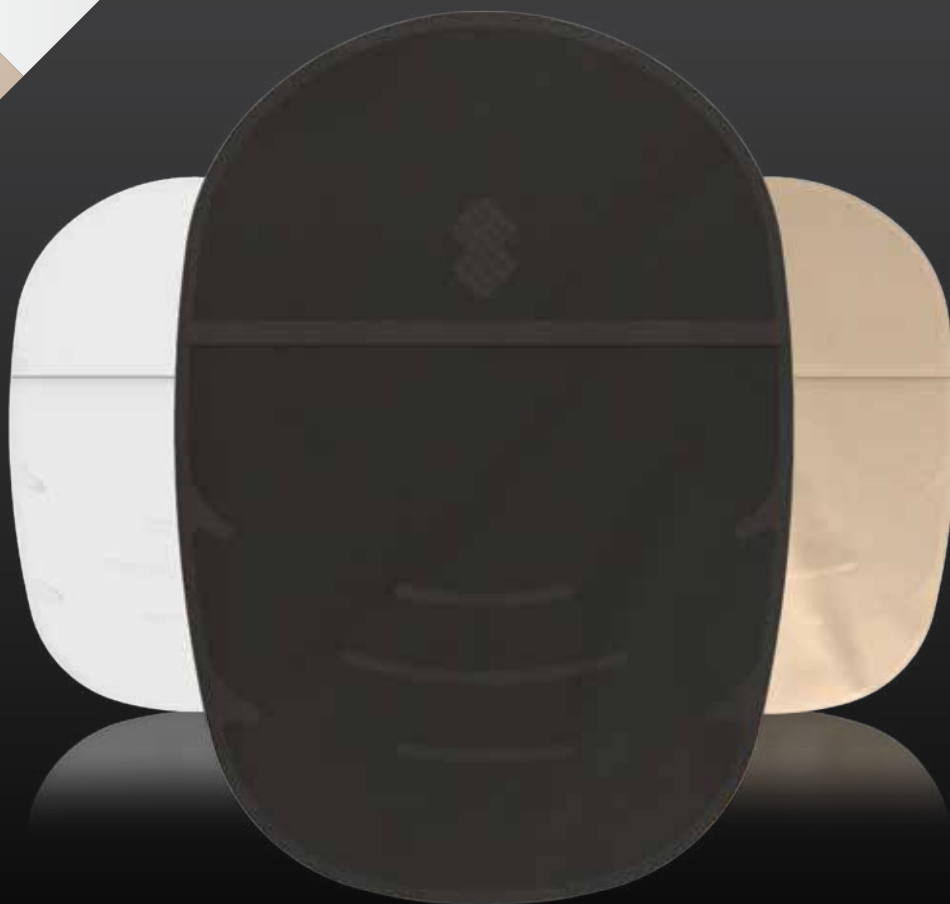
Volunteers' week took place during the first week of June and was an opportunity to say THANK YOU to all our volunteers. Amongst a number of other activities, we joined together using 'Zoom' for three virtual 'Coffee Mornings'! In total 23 volunteers and three members of the team attended. One session was dedicated to new volunteers. Everyone introduced themselves and said what they enjoyed about volunteering with **Colostomy UK**. Many also shared their 'stoma' stories and talked about where they felt most able to make a difference in their volunteering role. It was also a great chance for me to finally 'meet' everyone in person.

In the lead up to these coffee mornings I wondered if I had been over ambitious. I had some apprehension, mainly around getting the technology to work! I was also concerned that a coffee morning might be 'Zoom bombed' by smaller members of the household...but I needn't have worried. Our volunteers embraced the technology and 'virtual mingling' with their usual enthusiasm. As you can see from the post meeting comments below, they proved to be a great way for the team to catch up with others who they hadn't seen for a while or indeed 'meet' for the first time!

"It was great to see all of you and I really hope we can continue to do something similar in the future. It's a great way of helping us as volunteers remember that we're part of a nationwide team".

"I think Zoom meetings are one of the great things to come out of lockdown...I think they will be useful in the future, whether we ever get to normal times or not!"

Following this success, we hope to hold more 'virtual' gatherings. It also reinforced our thoughts about delivering some of our volunteer training in this way too. In March we were forced to postpone until further notice the face-to-face training we had planned for this year. Like many other organisations we believe there are real benefits in delivering training remotely. We are working on this at present and will roll out our first training modules shortly! ■



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Rosemary Brierley: a tribute

from Jackie Dudley volunteer and
member of *Tidings* Editorial Board

We are going to say a fond farewell to Rosemary Brierley a very valuable and long standing member of the *Tidings* editorial team.

Rosemary's background is in the NHS and as an associate editor with the Open University. Since her retirement Rosemary has been awarded a Masters (with distinction) in Writing from Nottingham Trent University.

It was in 1990 that Rosemary received her colostomy and with her great understanding of what it was like to live with a colostomy she wanted to help others and so became a volunteer for the **Colostomy Association** in 1996. Always active, Rosemary began her 'volunteering' career attending open days and taking calls on the 24-hour helpline (something that she still does today).

In 2001, Rosemary started writing items for the then 16-page *Tidings* magazine and in 2006 she became editor. She remained editor until 2008 when she retired from the position so she could concentrate on her own writing, producing articles and short fiction stories which have since been published in journals, anthologies and magazines.

Rosemary has always been a very active volunteer for **Colostomy UK** (both now and

when we were known as the **Colostomy Association**). At our request she returned as assistant editor in 2010 before going on to do another stint as editor from 2014–2017. Having been on the editorial board myself for well over a decade, I know we are going to miss Rosemary's calm influence. It's also thanks to her hard work as editor and more recently as a member of the editorial board, that every single issue of the magazine is packed with useful and informative articles. Under her guidance and leadership, and while supporting interim editors of *Tidings*, the magazine has increased its readership and gained respect in the medical world.

We shall miss Rosemary greatly. She has always been a valuable and committed member of the *Tidings* team, travelling from Nottingham down to Reading for each editorial meeting. Having read her amazing and gripping first book: *A Bletchley Park Wren Overseas* and recently her latest book *The House of Help*, our loss is definitely the literary world's gain!

Rosemary does not participate in social media, but would be pleased to hear from her readers.

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www.rosemarybrierley.weebly.com





2019 was in some ways a great year...I was lucky enough to take holidays in the sun, attend festivals, travel with work, focus on my fitness and have a busy social calendar. It was also the year that a surgical mishap landed me in a strange parallel universe where I was abruptly faced with my mortality, admitted for two life-saving surgeries and ultimately adjusted to life with a Stoma. My story starts in January 2019.

After 12 months of investigation, my husband and I finally got our fertility referral in January 2019. Three consultations and lots of tests later, we found ourselves in May being offered a place on a trial for a new instrument which would enable a non-evasive method of ovarian drilling (a process proven to stimulate ovulation). We were excited to take part, hoping not only would we benefit, but so too would other people in the future.

I had this operation in June as a day case. It involved a keyhole camera as well as the instrument that performed the ovarian drilling. Afterwards there was some discomfort, but nothing of concern. Eight days later, everything changed. I started experiencing abdominal pain. I tried to fix this with a hot water bottle and a lie down, but it got steadily worse, to a point where I could barely move. 111 advised me to see an out-of-hours doctor within the next two hours. The only available appointment was with a doctor 35 minutes away. By the time I arrived I was in excruciating pain. So much so, that after applying one bit of pressure to investigate my abdomen, the doctor stopped immediately as I recoiled

in agony. She called through to A&E and said we needed to go there straight away. I struggled to stay conscious during this journey, as my condition worsened. When I arrived I was barely able to function. It was a busy Saturday night, but I was taken through in a short time and eventually given some morphine to help with the pain.

Over the next three hours, I had a CT scan and a chest x-ray and visits from gynaecology and colorectal doctors as they tried to establish what was wrong in light of my recent surgery. I was showing signs associated with a bowel perforation. This is a critical condition, which can quickly lead to sepsis, so it was decided to urgently take me into surgery to investigate. A perforation was found in my small bowel. The damaged bowel was removed, my bowel reconnected, 11 litres of water was used to flush my internal organs, I was put back together, and woke up in the High Dependency Unit (HDU). I was in a lot of pain, but had fantastic care and pain relief. It was thought the ovarian drilling was the culprit with the exact cause unknown, but at this stage my focus was on recovery.

I started to make good progress. I was out of bed and moving around, eating small portions and laughing with my visitors and the wonderful HDU team. A sign of a successful resection is breaking wind, so I was eagerly seeking the holy grail of a satisfying trump. Unfortunately, this never came. Four days after my surgery, I woke up feeling particularly under the weather. I passed up any visits that day, thinking that I might just need a rest. My temperature began to spike, along with abdominal

pains. The nurses took no chances and raised the alarm straight away and I was quickly taken for a CT scan. It showed air bubbles suggesting that the resection had failed. This was a known risk because my body had been so inflamed when the resection was made, making healing all the more challenging. My husband was already with me as I feared bad news was on its way. My parents were called in urgently as I needed to be taken into surgery as soon as possible. This time, I was told that a stoma was the only option to keep me safe and allow my body to heal. By this stage I was extremely unwell. Arrangements were made for me to go into Intensive Care (ICU) following the surgery. On the way to theatre, I had made peace with the fact that if I didn't come out of this operation, I would just be happy for the pain to stop.

I had an extremely uncomfortable 24 hours in ICU. I had an arterial line stitched into my neck with multiple lines attached to supply the necessary antibiotics, fluids and pain relief. I had a visit from the stoma nurse, who started to tell me about my stoma. I had an end ileostomy. I had no idea what this was, but later learned that my large bowel had been completely closed and the other end (my small intestine) was fed through my abdomen to function on the outside of my body while the inside healed. Basically, I now pooped into a bag attached to my stomach rather than the usual exit.

I was eventually moved back to HDU, much to my relief as ICU is a frightening place. Back in HDU, I started to make progress and received daily visits from the stoma nurse. I forced myself out of bed, forced



3 weeks post-op



4 weeks post-op
discovering new clothes



10 weeks post-op

A DREAM

ected Events Dawn Clarke

10 weeks post-op – enjoying festival life

myself to eat small amounts and slowly tried to acquaint myself with my stoma. At first, I was not able to look at it, but by day three, my fantastic stoma nurse started to reveal it to me bit by bit. I was told that until I could care for my stoma, I would not be able to leave hospital. This was motivation enough to face the fear and forge a relationship with my new friend.

As a 34-year old body-conscious woman, I was curious how I could adopt this stoma into my life. So many questions...could I enjoy the foods that I love? Could I wear my favourite clothes? Could I get back to running and exercise? How often do I empty the bag? Will it smell? Can I travel and will I get searched at the airport? I discovered the answer to all of these questions and many more over the coming weeks.

After 15 difficult days in hospital, I was sent home. I had become rather institutionalised in the safety of HDU; there was a frightening sense of vulnerability when I got home. It felt as though everything was a 'first'. The first time I emptied my bag, the first time I changed my bag, the first time I took a shower or bath, the first walk outside, my first trip to a local cafe. Everything felt new. I set myself daily milestones every single day. Some days were harder than others, but my incredible husband, family and friends, lifted me up when I ran out of steam. I spent some quality time with my mum who made sure I took at least one walk, however short, every day. My husband and friends encouraged me to go out, attend gatherings, meet for lunch etc. I made a fantastic friend who shared her stoma experiences with me and helped

me figure out how to find a new 'normal'. It became quickly apparent that I was not alone, and there were so many inspiring young people who proudly shared their stoma experiences and tips.

To begin with, I struggled to find the right appliance and suffered leaks. Whilst the 'output' never broke through completely, there was always a fear that it would. There was a constant cycle of one step forward, two steps back. My biggest challenge was at seven weeks' post-op when my husband had arranged a short break to Menorca for my birthday. I bought some high-waisted bikinis which concealed my stoma bag and felt fairly confident that I knew what I was doing and I could manage without my stoma nurse on hand. It was challenging and I had some wobbles but, overall, managed to enjoy myself. I felt like I'd achieved something big and whilst I was a long way off knowing everything about my stoma, I'd come a long way.

Over the next eight weeks, I focussed on getting my fitness back and returning to work: things that helped me feel 'normal' again. Not many at work knew what had happened and this transition was handled sensitively which I am forever grateful for. Fitness wise, by 16 weeks' post-op, I ran my first mile. By 22 weeks I returned to netball. This was a huge and emotional milestone for me, as getting back on court was one of the last things from my pre-stoma life I wanted back. Physically, I found there were few limitations with a stoma.

The situation also came with psychological strains. I had some very hard days where I was overwhelmed with a sadness that I had gone into a process to help my husband and me start a family, but came away with a stoma. No amount of telling yourself how lucky you are to be alive can remove that sadness. I addressed this quickly and sought some therapy to help me through this challenge. It worked well and after four sessions I

was able to balance my thoughts and had methods to help me with the darker days.

Normal life resumed and I enjoyed a fantastic Christmas and New Year. As soon as 2020 came, the countdown began to my reversal. On 5 March I went for my surgery. This was open surgery to reconnect my small bowel to my large bowel. There was a lot of pain and apprehension, but as this surgery was planned, it was an entirely different experience to the emergency surgeries of 2019. The holy grail of the trump came and I have to say it was the most satisfying trump I have ever experienced, not having done one for nine months! After just four nights, I was sent home to recover...and so the process started again, but it was easier without the trauma. I considered myself lucky to have had my surgery as days after, planned surgeries were cancelled as the hospital prepared for Covid-19 cases. Covid-19 lockdown has coincided with my recovery time, so I have used this period to recover and work on my fitness.

Reflecting on this series of unexpected events, I am proud of my approach in the face of terrible adversity. There were two options: either let this consume nine months of my 30s or accept that plans have changed, adjust, and make a new plan. Option two wasn't an easy one, but

was by far the better option long term. I am proud of my stoma, it saved my life (along with some clever surgeons!). I am endlessly inspired by those who embrace theirs. There should never be a stigma associated with stomas. Are they different and unusual? Yes. Is it anything to be afraid of or embarrassed about? Absolutely not. ■



7 weeks post-op
birthday cocktail in Menorca



22 weeks post-op
back to netball



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Diverticular disease: A new research project

Glen Saffery – Research Coordinator

Diverticular disease and diverticulitis are related digestive conditions that affect the large intestine (colon). In diverticular disease, small bulges or pockets (diverticula) develop in the lining of the intestine. Diverticulitis is when these pockets become inflamed or infected.¹

Diverticular disease is a common problem

Although present in only 10% of people under 40 years of age in the UK, over 50% of the population aged over 50 are affected. This rises to 70% by 80 years of age.*

The consequences can be life-threatening – with serious diverticulitis requiring emergency surgery. Yet most people have never heard of it, and it remains something of a mystery even to those who have it – and their doctors.

That's why the Bowel Disease Research Foundation (BDRF) has awarded £30,000 to launch an international research project to better understand diverticular disease. The team have now recruited over 130 hospitals, covering every continent!

Earlier this year, the Royal College of Surgeons of England played host to an event bringing patients and our research team together. Many of those who came now live with a stoma due to diverticulitis surgery. For them, this has not only saved but drastically improved their lives. The day was a fascinating and rewarding experience for all concerned – on both sides of the proverbial consulting table.

The first session of the day focused on symptoms – normally an easy area to define, but surprisingly complex with diverticular disease. Many patients were initially diagnosed with other bowel problems, due to the broad range of symptoms. Most patients had never heard of it until diagnosis, so never suspected they might have it.

Some patients suffered sudden, agonising pain resulting in emergency hospital admission, while others saw a more gradual build-up. Others had no symptoms at all – only diagnosed alongside other conditions.

“I feel like I’m living in a fog”

Discussion moved on to the consequences and impacts on daily life. These were enormous – the overwhelming themes were crippling uncertainty, fear and severe effects on quality of life.

One patient told us:

“The fear of the unknown was the hardest part, it was out of my hands and I had no control over the situation.”

Another said:

“I feel like I’m living in a fog.”

These sentiments will doubtless feel familiar to patients affected by many other forms of bowel disease – from Inflammatory Bowel Disease (IBD) to cancer and the side effects of treatment, like Low Anterior Resection Syndrome (LARS).

Patients described constant anxiety about knowing where the nearest toilet is, fear of going out in public and of when the next flare-up could strike.

CONTINUED ON PAGE 17, COLUMN 1



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CONTINUED FROM PAGE 15, COLUMN 2

Diet was also a minefield – sometimes there was a clear pattern between diet and flares, but for others there was no rhyme or reason.

The consensus was clear – diverticular disease can take over and ruin lives, and we need better ways to fight it.

"I put a lot of trust in my surgeon being able to do what they said they could do."

The third session focused on treatment – namely the variations and in some cases lack of effective treatment.

Once again, a broad range of experience was on show. Some patients had gone through numerous courses of antibiotics, others had surgery, and others no treatment at all.

For many in the room, the problem had become severe enough to need drastic surgery. Often, this resulted in a temporary or permanent stoma. Perhaps contrary to some expectations – even those of the patient themselves, these had restored rather than reduced quality of life. Some had turned down surgery to reverse their stoma – so great had been the positive impact on their daily lives.

Information about the options when facing treatment was a major theme of these discussions. Most patients felt they had been crying out for more knowledge that simply wasn't there. One of the surgeons present said: "Often we're asked, 'what would you want done if it were you?', to which the answer is often 'I just don't know'".

Timing of being offered surgery – often earlier than at present – emerged as an important concern. Broadly, patients wanted to feel more in control, and the research team gleaned some vital information to feed into the study design.

Screening, genes & data sharing – what does the future hold?

Proceedings ended with a discussion of research methods and ideas.

It was an incredibly inspiring discussion, with unanimous agreement that research was vital – and huge willingness to participate out of a desire to help others. Patients would not hesitate to donate what was required to assist researchers – from stool samples to colon biopsies and blood tests.

The dream was to see a simple blood test developed, or a method of screening for diverticular disease, that could pick it up early and enable those affected to manage it.

Huge passion for discovering the root causes was also clear – genetics were thought to play a part, but a better understanding of the many complex issues at play was considered a huge priority.

BDRF would like to thank every single participant in the day. We're very excited for the potential of this work to shed light on a problem that is all too common, but still so poorly understood.

Together we will make strides in furthering the research in order to improve treatment and people's lives.

If you would like to find out more about this work or any of our other research, please don't hesitate to visit: www.bdrf.org.uk You can contact us at: gsaffery@bdrf.org.uk or on 020 7869 6946 with any queries. ■

¹Source: NHS website

*2014 Commissioning Report – *Colonic Diverticular Disease* by The Royal College of Surgeons and the Association of Coloproctology of Great Britain and Ireland.

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



Celebrating my 90th birthday, August 2018

Still Tap Dancing at 91

Iris Ford

At the age of 74, I noticed some drops of blood in the toilet pan. Knowing that my mother had died of bowel cancer at the age of 51, I was dreading, but not surprised to learn, that I had a tumour in the colon. I was warned that I might have to have a colostomy and even had the position of it marked on my stomach the day before my operation. I awoke after the operation relieved to find out that this had not been necessary. Although the tumour was cancerous, the surgeon was confident that he had got 95% of it out. He also didn't consider that chemotherapy was required. On balance he felt the likely difference this would make to the remaining 5% was outweighed by the other effects that chemotherapy would have on me.

I was, however, left with a very 'loose' bowel which caused me many problems and I soon got to know all the local toilets. Over time (and with the aid of Loperamide tablets) my innards settled down and I had many carefree years, swimming in different seas, returning to the over 50s tap dancing class I had joined on retiring at the age of 62.

As well as enjoying the dancing, another benefit of being a member of the class has been the support of my dancing friends.

This was never more so than in late 2014, when I started to notice blood in my stools. I didn't delay going to the doctors and after various tests and examinations it was discovered that a polyp was the cause. On 24 November 2014 I was booked in for surgery at Barnet Hospital to remove it. I was expecting to be in hospital for about four days, but ended up having a two-week stay and going home with a loop colostomy! This was because when the surgeon opened me up, he found that the polyp had fused with my rectal wall, which meant that he couldn't remove it without doing a colostomy. The polyp itself was found to be turning hard, which is apparently an indication that it might be cancerous.

Like other readers I found the initial post-op period in hospital challenging. I had a few accidents and problems with things like bags bursting. This was one of the reasons why I didn't go home for a few weeks after the surgery. Having always been very independent and living on my own, I wanted to be confident about doing bag changes first. Thankfully, Margaret, the stoma care nurse assigned to look after me was excellent. She helped me while I was in hospital and then, in the early days, visited me at home after I was discharged.

Leaving the hospital was still scary though. My daughter was afraid I wouldn't cope. I was an 87-year-old widow and a fresh air fiend, who had never seen a stoma bag before. I have always been particular about



Birthday celebration in London, 2017



With best friend Joan and sister-in-law Pauline, Warner holiday resort

smells and as I very worried about this, my daughter filled the house with room fresheners etc but my concerns turned out to be unfounded, as others couldn't smell anything. I was also scared to go out to begin with. These fears weren't helped after having a few accidents at home. But eventually I plucked up the courage (always taking spare clothes and bags with me and knowing where the toilets were situated!).

A couple of months after my surgery I developed a large parastomal hernia which was very painful, even when wearing a hernia support belt. I had had no warning that a hernia could develop. Although I couldn't do much lifting due to arthritis in my wrists, up until this point I had continued to enjoy walking, gardening, shopping and of course dancing. Unfortunately, the hernia restricted what I could do, but while I waited for hernia repair surgery, my lovely family arranged many outings for me. One included a weekend at the seaside, where they had hired a wheelchair and wheeled me down to the sea to have a paddle!

In May 2016 I had a hernia repair, but this only lasted a couple of weeks before it started to protrude again. Fortunately, the pain was so much better and with the help of a support belt I was able to start tap dancing again. I knew that further surgery was impossible having been told that at my great age my skin was very thin and wouldn't take it. This was a nuisance, as it meant that I had to get rid of some of my favourite clothes as they wouldn't fit or look good over my one-sided bump. I might be getting on in years, but I am still fashion conscious and like to look my best.

As well as re-starting my tap dancing, I was determined to have one last swim, so I sent away for a bikini with a skirt. I was able to realise this ambition after joining the Ostofriends Support Group in Potters Bar. Peter, who runs the group, organised a special afternoon where we had a section of the local swimming pool just for members. I entered the water clad in my bag, the hernia support belt (which I need to wear all the time), pants to prevent

the belt Velcro pulling on my bag and lastly the swimming skirt. I was in heaven swimming again at 90 years old with no fear of the hernia being kicked when passing another swimmer.

My post-stoma surgery exploits haven't been limited to tap dancing, swimming and paddling in the sea either...at first, I vowed I could never board an aeroplane again, fearing problems with my bag. But after reading articles about travel in *Tidings* I changed my mind. My first flight as an ostomate was to Edinburgh, where my daughter and granddaughter (carrying my case!) took me to a music festival; we ended up dancing in the street in warm sunshine.

This jaunt was followed the next year by a flight to Miami with my daughter, son-in-law and a friend. After we arrived, we then embarked on a Caribbean cruise. The highlight was a swim in Montego Bay, Jamaica. I was in heaven again. The family organised wheelchairs at the airports which made things very smooth, although at Miami on the way home my hernia showed up on a screening. This caused a slight problem. I think for a moment they thought 'this old granny is carrying drugs or a bomb down her trousers'. After being frisked in a little room an older employee recognised the hernia belt was only covering my hernia and it was a medical problem. She had seen stoma bags before, whereas the younger operative hadn't seen nor heard of a stoma or hernia. I didn't mind they were only doing their job!

I do appreciate that I am one lucky old lady with such a loving supportive family of two children, two grandchildren and their partners and now four great-grandsons, plus all the friends I have acquired over the years I have been around. Nobody wants to have stoma surgery, but my message is: don't let it get the better of you. Once you have recovered from the surgery, get out there and enjoy life while you can! ■




Drinks with granddaughter Stephanie, before going to a play. Wine suits better than coffee!




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Grandma needs a teddy

Nicky Norman



I haven't done anything heroic like climbing Kilimanjaro or swum the channel, but I think my road to an ileostomy is maybe a little different.

On the first weekend of December last year our family travelled to Norfolk where we surprised my brother on his 80th birthday. We stayed in various cottages in a small village called Hindolveston. It is a very quiet place with no pub.

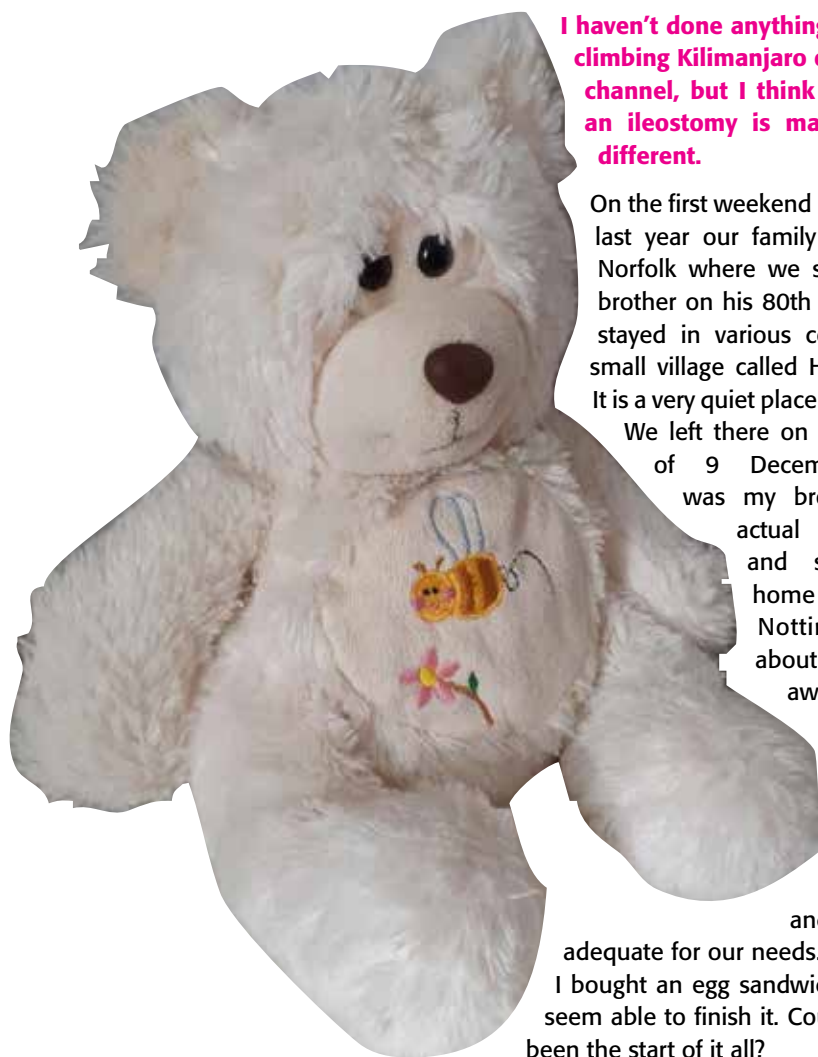
We left there on the morning of 9 December which was my brother Tony's actual birthday and set off for home in Brinsley, Nottinghamshire, about 3½ hours away.

We always have a halfway stop at a transport café. It's a bit rough

and ready but adequate for our needs. I remember I bought an egg sandwich but didn't seem able to finish it. Could this have been the start of it all?

That evening Tore (my husband) and I went to our choir practice in West Bridgford. The West Bridgford Liberty Singers are run by our daughter Kari. We got home at about 10:30pm and at that point I was feeling fine. All was well until 3:00am the next morning when I awoke with tummy pains. I thought it was something I had eaten (maybe the egg sandwich?) and the nurse at the surgery thought the same and gave me some Buscopan. Unfortunately, the pain got worse and so the next evening I rang 111 and was prescribed codeine which my husband had to collect from Nottingham at 1:00am the next morning. I spent the following day and night in pain. On the Thursday morning we decided to attend our doctor's surgery. My doctor asked me several questions most of which I couldn't answer due to the pain. My husband had to answer for me. I do remember the doctor saying: "Is your tummy usually this distended?" and "When did you last pass urine?". He also asked an odd question about what my sick was like. I remember saying: "No" to distended tummy, "probably 24 hours" to the passing of urine and that when I had vomited it "wasn't like food". He looked very worried and left the room. He returned saying he had rung for an ambulance and asked for it to be urgent. I waited about 25 minutes I think and then I was whisked away to

CONTINUED ON PAGE 23, COLUMN 1



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CONTINUED FROM PAGE 21, COLUMN 2

Queens Medical Centre in Nottingham. I think the sickness was probably faecal matter which couldn't get any further down the digestive system. Unfortunately I had to go first to A&E which was an education in itself. Luckily I was oblivious to what was going on. My husband had to go to the nurses' station twice to ask for something for my pain.

I really can't remember much after that. My husband had to fill me in on the details later. In essence, following blood tests and scans etc, it was decided to operate immediately. My blood tests had come back abnormal and there was a possibility I could be looking at dialysis for the rest of my life. They operated late that evening and left my wound open for 24 hours to be sure they had got "all the worrying bowel" removed. I learned afterwards that my appendix had stuck to the inside of my abdomen and my small bowel had wrapped around it and cut off the blood supply. I was sedated for a few days. They removed one metre of my small bowel and I was in intensive care for seven days then on the ward for a further seven days. I don't remember an ileostomy being mentioned to me before I went for surgery, but my husband said it had been talked about. However, I wasn't at all surprised when I

woke up with one. My husband has had a colostomy for 20 years so that certainly helped make the practicalities of having a stoma easier.

During my stay my family were able to visit and one of my grandchildren, William aged eight, said to everyone "**Grandma Needs a Teddy**". And so he brought me one of his white fluffy teddies which I still have. I can remember the vivid dreams I had while in the hospital and can still remember them six months later. They weren't nightmares but seemed unbelievably real; quite worrying really as I was accusing my family of a conspiracy to keep me in hospital!

I have to say the nursing staff, doctors and stoma nurses were amazing. I didn't feel I needed to worry about anything. Whatever the problem they sorted me out and I was able to go home on Christmas Day. I feel sure that what happened to me was unusual and in fact when the surgeon visited me he said the same and my GP said I was very unlucky. I must have had inflamed appendix but it was all so sudden, and I think I am lucky to be alive albeit two stone lighter.

The support I have had from health professionals and my husband has made coping with my stoma much easier and feel proud how well I have handled the

situation. Tore's 20 years' experience of living with one was invaluable. As I am sure you can imagine, he was able to offer a special kind of support. Learning to walk again was a challenge having spent most of the 14 days this 'event' lasted in bed! As I write this, my kidney function and liver function are getting back to normal and I am a candidate for reversal. Of course I don't know when that will be, due to the coronavirus, but you can be sure that when I do go back into hospital, Teddy will come with me. ■



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www.ColostomyUK.org



Plodding on with life again

Tina Tibbs



I have been an avid reader of *Tidings* for a few years now and over this time I have found learning about the lives of other ostomates very supportive.

In fact, it was this that encouraged me to put pen to paper. In particular, I am hoping that what I have to say might be of comfort to those who have just had stoma surgery or are just about to go through it. My experience might also be of value to people who are facing that difficult decision about whether to go ahead or not – even if all my story does is to confirm that the turmoil they currently feel is entirely normal under the circumstances!

In November 2016 I visited my GP with what I believed was piles. She examined me but couldn't find anything. When it came out in our discussion that it was thought my grandfather had died of bowel cancer, she took the precaution of referring me to the colorectal department at Cheltenham General Hospital. My appointment came through quickly. After examining me, the consultant said that he could definitely see something 'up there', which he thought was a polyp. This was subsequently confirmed to be the case but, due to its size, the polyp had to be surgically removed. Hence, at the end of December, just a month or so after seeing my GP, I found myself on the way to operating theatre.

The surgery seemed to go to plan. I was at home recuperating when I received a call from a colorectal nurse at the hospital. She said that the consultant would like me to come in, because the tests they had done on the removed polyp had revealed a 'little bit of cancer'. As you can imagine, I was very shocked and worried, and these feelings went up a notch when I went to see the consultant. In his room, were also two nurses (I now know they were stoma care nurses), and the consultant started to talk to me about having a colostomy bag. I was given some information to read about anatomy and the bowel and booked in for a further discussion. This was just as well because in my shell-shocked state I couldn't really think clearly.

After much thought and deliberation, I decided that I didn't want to have a stoma. I was going to be the exception. How could I ever agree to have a 'thing' like a bag stuck on me? At the time I didn't really know much about stomas and colostomy bags, other than all the things I now know aren't true, such as they are 'an old person's thing' or that people with them smell etc. This played a part in my decision. In addition, I knew from the consultant that there was no going back from the surgery that was proposed. Therefore, determined to keep my bowel, I insisted on having treatment before going down the surgical route. Taking responsibility for my health in this way was empowering. Even now (and knowing what happened afterwards) I don't regret this decision. If I hadn't tried the treatment first, then I would have forever wondered if having a stoma was really necessary. This is, of course, my way of thinking. Others in the same situation might approach things differently. The important point is to be comfortable about the choices you make.

In January 2017 I started a six-week course of radiotherapy, comprised of 30 sessions. I found this very difficult, especially the burns and the tiredness. My two sons and my daughter were very supportive, as were my employers, who even organised a rota to take me to the hospital! Once the radiotherapy finished I had a short break before starting three months of chemotherapy, after which I went into remission. It was at this point that my consultant announced some incidental findings, namely a growth on my thymus gland and growths on my ovaries. Hence I finished 2017 as I started it, in hospital, where I had the growth on my thymus removed. Luckily this proved to be benign.

I began 2018 full of hope, particularly when I was able to go back to work. At this point, my resisting stoma surgery seemed to have paid off. But, as winter moved into spring, so the problems started. I was dashing to the loo every 15 minutes and had a gnawing

pain. My quality of life was awful. I knew every single toilet in town and, at the end, became housebound. Still under the care of the hospital, I had another colonoscopy, but by now I knew the cancer was back. It was no surprise when the consultant said: "We need a little chat." In July 2018, the inevitable occurred; I underwent stoma surgery. This was rushed through as I was so poorly. The operation took nine hours. I had a large section of my bowel and colon removed, both my ovaries removed, as well as my pelvic floor and coccyx.

After the surgery, I underwent another six months of chemotherapy. I also went through all the ups and downs one has with a new stoma and which others readers have spoken about so eloquently in their accounts. Most recently, I have developed an adverse reaction to the brand of bag I have been using. But even during lockdown I was seen quickly by a stoma care nurse at Cheltenham General Hospital; I really can't fault the care and kindness shown by the team at their stoma clinic. But rather than talk through my experiences with regards to stoma management, I wanted to finish on a high note. Although I resisted stoma surgery (and as I said earlier don't regret having done so), I can honestly say that my stoma has given me back my life. I am now in remission and am back at work (albeit working from home – but that's down to COVID-19 and nothing else!). I no longer have to rush to the toilet. I have also managed four trips abroad since my surgery, which has included swimming in the sea and being dragged up on stage to dance! I've also learned that it is possible to do a bag change in an aeroplane's toilet cubicle... These are things that I simply couldn't have contemplated doing just a year or so ago. So, if you are recently post-op, I hope you take heart from my story. In time, the good days will start to outweigh the bad, even if that doesn't seem possible to you now. Before you know where you are, you will be plodding on with life again. ■

Dancing in Their Light

Jo-Ann L Tremblay
Ostomate
Author



Ed's note: Regular readers will know that in the last couple of editions we have been giving some focus to the challenges that young ostomates and their families face. The piece below is the second and final installment from Jo-Ann Tremblay, which reveals that these challenges seem to transcend national borders!

I am the resident "Ostomy Lifestyle Expert", with the Ostomy Canada Society (OCS), Medical Advisory Committee (MAC).

I have the responsibility of receiving and responding to a wide range of ostomy-related questions from the public, via the ostomycanada.ca website. Together as part of my Paediatric Ostomy Awareness commitment, I have the honour of working with several paediatric ostomy families, our goal is to shine light on Paediatric Ostomy.

My article *The Littlest Ones* appeared in the summer edition of *Tidings* and featured four-year old Mallory and her family. Mallory had stoma surgery shortly after she was born. In this final part of my Paediatric Ostomy Awareness and Advocacy series, I am pleased to offer *Dancing in Their Light*, which features paediatric ostomate, 14-year old Delia, and her family.

Delia's journey began at eight years of age when she spent four weeks in hospital. Inflammatory bowel disease (IBD) was the diagnosis. At nine, she developed *Clostridium difficile*. She was very ill. The medical professionals administered various infusions, bowel rest, and other treatments. Nothing was working. After five weeks in the hospital, a portion of her colon was removed and an ileostomy was created.

Her mother says: "The surgeons have offered Delia the opportunity to have a J-Pouch constructed. Delia currently prefers to make her ileostomy permanent, and we support this decision. At 14, the surgeons feel Delia is too young to make this decision and want her to wait, continue with scoping and revisit the question in one or two years."

Delia illustrates and writes. Her characters are drawn with an ostomy. She has made her own ostomy doll, and created an ostomy bag for it. Delia and her family feel there needs to be more representation for kids in books, toys, and the media.

"There were no professionals specialized in wound and ostomy care assigned to us", says Delia's mother. "We eventually got a paediatric home nurse, but she was not experienced with

ostomies, so we discontinued. We once went to a wound care unit at our local hospital, but needed special permission to get an appointment, because they didn't take kids. We didn't find them helpful."

"My biggest challenge is the medical community I deal with. They seem to prefer J-Pouches to ostomies. I think they are finding it hard to believe that my child can be this comfortable with her ileostomy. They are putting off surgery, in order to wait for her to change her mind. I think this shows lack of respect for her intuition, her choice and her decision. I think this medical bias is a reflection of the greater society's attitude toward bodies and ostomies," says Delia's mother.

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 society, and through social media.

Delia and her family are not in a region with ostomy support. "There are no groups in our region for parents of kids with ostomies. There is a support group for parents of kids with IBD, but none of their kids have ostomies," says Delia's mom.

"We belong to some social media sites for people living with J-Pouches and ostomies. The sites have helped us get answers quickly, as well as allow us to help others. This has also helped both Delia and me to feel connected to the community of people living with ostomies, which is important to us. In some ways I feel isolated. We have only met two other families with children with ostomies. One is getting it taken down soon, and the other was very shame based and kept his hidden. This was not helpful to Delia, because she has taken the approach of embracing and accepting her ileostomy," Delia's mom confesses.

As ostomates we are consistently aware of what we eat, our output patterns, our pouching system status and so on. Parents of children with ostomies have these challenges and much more.



"I worry about Delia's hydration, obstructions, and hernias. So, I make sure she is taking precautions. I get sad that she continues to struggle and she gets tired easily. So, I worry, as all parents do. I educate her about these realities and risks, so she can be safe and enjoy her life," comments Delia's mom.

Body image for those of us with an ostomy is a challenge at any age. In the case of the children they are developing their self image. The parents of children with ostomies are addressing this issue as well.

"We use humour with Delia to deal with all the challenges and an attitude of acceptance and honesty. We try to live life fully. I am determined that Delia see this as a small part of a big and wonderful life. I don't want her life to be a medical life or the ileostomy be her identity. Nor do I want her to see it as anything to hide. I wanted to de-stigmatize it immediately. I was very clear with family and friends that we were going to be open and honest about it, not whispering about it in shame," Delia's mom said.

"It is part of her, she can share or not share. That is her choice. When she first got it, she asked if it was a private body part. I said: 'No. It is not.' She was relieved to hear that. She asked the night before the surgery if she would still be herself once a major organ had been taken out. I said: 'yes', and explained she was not a body. None of us are. We are so much more. Being nine at the time, she accepted all this without question. She is confident in herself as a person with value. She continues to feel good about her body at 14, in a culture that does everything to undermine that," explains Delia's mom.

Paediatric ostomy parents are creative and innovative. The following are some skills and tips they want to share:

- ❖ Talk with your sources, request sample products, play with ideas. It's medical arts and crafts, you have to play a bit to figure out the perfect combination.
- ❖ Let your child control their privacy level. If your child wants people to know about the bag, we can help explain it to others. If the child wants to keep it private, we help them do that too. Our children were not in control of what happened to them, but, they are in control of who knows about it.
- ❖ Children are people and when they have a medical issue, they are the authority of what's best for them.

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 families have important messages they want to pass on.

Delia and her family want everyone to know; "Having an ostomy doesn't change who you are. You can love yourself well, embracing whatever challenges you have. There is no shame in having an ostomy. If more people showed their bags, the stigma wouldn't prevail."

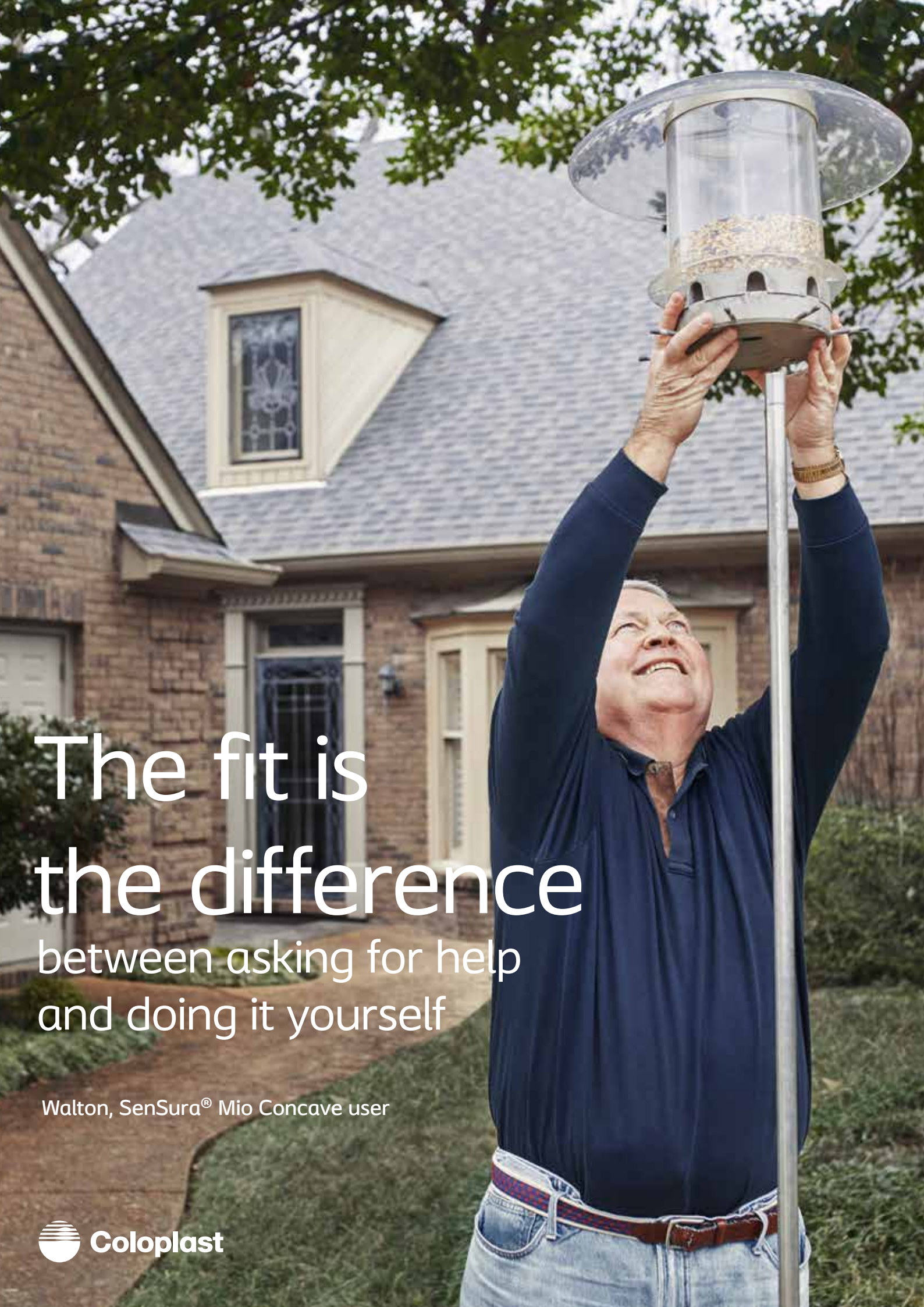
"You can't look at an ostomy as a negative or as a failure. It can be the best thing that ever happened. It saved Delia's life and we've learned acceptance. If you want a J-Pouch, that's okay too. It is up to the person who is going to live with the choice. No choice is wrong, if it's your choice. Judgement is bad and when people judge, it's about them not you," says Delia's mom.

Delia, and her family are working together to shape Delia's fearless spirit. As parents they embrace their role as medical parents.

The littlest ones and their families are extraordinary. Sometimes in life, moving forward takes bravery. Ostomates of all ages can attest to that. We do our best to run towards, not away from the challenges. We muster up the courage to stand up and face our realities. Having a life saving ostomy sure has a way of testing us, rewarding us with a second chance at life. As the Paediatric ostomates dance in their light, they 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. ■



"The things that make me different are the things that make me, ME." – Piglet



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

OC_ColostomyUK_Summer_Concave_19/20



Poppy's World Cruise

Jill Woodward

My husband and I booked our world cruise over a year in advance and chose it because part of the itinerary included New Zealand, where both our daughters live with their families.

A cruise seemed a good option as I didn't fancy a long flight with Poppy (my stoma). I also have a chronic bad back, which gets very uncomfortable on any long journeys, especially when moving around is difficult, as it is on an aeroplane.

As the cruise ship wasn't sailing from Southampton until 3 January 2020, I had plenty of time to plan everything. This was needed, as we were going to be away for 82 days. It would have been even longer, had we not decided to do the last leg (Dubai to England) by air. There was lots to consider, such as what clothes and shoes to take for a voyage encompassing different climates? And what supplies would Poppy need for such a long period? Plus, what luggage space would they take up!

Travel insurance was the first challenge. Going away for so long, coupled with my pre-existing medical conditions, plus having had bowel cancer and chemo three and half years ago, meant that the premiums were high. Our first quote was over £6,000 and other cheaper quotes wouldn't cover any medical emergency on the cruise if I had to be helicoptered off and/or repatriated. Thankfully, we finally found an insurer that wasn't ridiculously expensive and covered everything.

Ed's note: It certainly pays to shop around for travel insurance. If you are thinking of going away, then contact **Colostomy UK** for a copy of our *Travel Insurance factsheet*, or download a copy for free from our website.

The next hurdle was house insurance. Normally, this wouldn't be a consideration for a holiday, but as our house was going to be empty for so long we thought we should check we were still covered. It was just as well that we did, because we discovered that our insurer wouldn't cover the house for the whole period of our trip. Hence we had to go to a company that insured unoccupied

properties. We also arranged for Royal Mail to hold on to our post until we returned, as we weren't insured if post was left in the house. Our lovely neighbours agreed to keep an eye on the house, which was a great relief.

Planning for Poppy was a military operation. She ended up having a suitcase of her own, which was bigger than the ones for us! I worked out that if I estimated using five pouches a day (I normally use between two and three, but know you need to pack far more when going away) I should pack over 400. I would also need the same number of waste bags; I have two types because I double bag. I use one adhesive remover spray every five days, so put in 18 to be on the safe side. I also needed: filter stickers; two large bottles of lubricating deodorant; two pairs of rounded scissors (I cut my own flanges); air freshener sprays; a large tub of Sudocrem (used for sore skin under the flange); bed protectors; numerous wet and dry wipes; plus other bits and bobs.

The next thing was to ask for three months of prescription medications. I also stocked up with several packets of Imodium, paracetamol, ibuprofen, toothpaste and, of course, lots of toiletries, as these items would not be readily available in some of the places we were visiting. I certainly didn't want to spend my time ashore hunting for things!

Well, after all this planning we finally got on board and I must admit I was pretty apprehensive about it as we were going to be away for such a long time. Poppy did have the odd blip, the worst being when I was put on antibiotics by the ship's doctor, due to an inflamed big toe. Otherwise, generally she was well behaved and didn't disgrace herself too often, though she did smell out the cinema on one occasion so I was really glad it was dark in there! She also decided to fill her bag during dinner one night and I had to dash back to the cabin to change, missing out on my dessert! I had to be very careful with what I ate and drank as certain foods upset Poppy. Red medical sacks were available for my stoma waste bags and they were taken away each day by the cabin steward, so no nasty whiffs lingered for long in the cabin bathroom!



We had some excellent stops on the way, but didn't book any whole day trips and just kept to half day tours, as you can't expect a coach to stop at a loo if your stoma goes berserk! I was also lucky that I only needed to change my bag on two occasions when out and about, and found the toilets were okay. It was also fortunate that we had calm seas for most of the cruise, as it was interesting trying to change my bag when the ship was rocking! I did find, however, that when we were in hot humid areas my bag's flange started to peel away from my skin. This was mainly because I wear special underwear, designed to support hernias, which made my skin even hotter!

We left the ship in Auckland to spend a few days with our girls, and to see the grandchildren again. We hadn't seen one of our granddaughters for four years and had never met her brother, who was almost a year old when we got there. Our other daughter had emigrated 18 months earlier, so it was lovely to catch up with them all and see their houses, the children's schools, and explore the area where they had settled. All too soon we had to leave and flew to Brisbane (just under four hours) to catch up with the ship. Poppy was okay on the flight but my bag did expand, so I let out some air by peeling back the filter sticker. I was careful not to let out too much though, as I didn't want pancaking!

While we were away, the coronavirus started to make its deadly presence felt and, as a result, our onward itinerary was changed. We were meant to go to places such as Shanghai, Singapore, Malaysia, and Hong Kong. Instead we had stops around Australia, going to Tasmania, Melbourne, Adelaide, Albany and Fremantle. Passengers who were due to leave us in Hong Kong had to disembark in Fremantle. We also were told that Dubai, where we were due to fly home from, had closed its cruise port and that the ship would be rerouted to South Africa, making stops at Durban and then Cape Town, from where we were now going to fly back. This obviously worried me as it would be a much longer flight. In the end though, South Africa went into lockdown so we didn't get off but only refuelled and restocked in Durban.

We then sailed straight back to Southampton, as all overseas ports were closed, and spent 32 days at sea without getting off the ship. We had a fuelling stop in Tenerife; it was nice to see the land again whilst at anchor! During this long sea journey the captain introduced social distancing, even though we didn't have Covid-19 on the ship. This made life harder as entertainment and social activities were curtailed. We had to keep one metre apart (not enough space for two metres

as it would have been difficult if you met someone when walking along the narrow corridors!). We think, though it was never really explained, that this was to show the Southampton authorities we were keeping safe. These restrictions made being stuck at sea much harder with not a lot to do, so we were really pleased to get home, even with all the problems here. Fortunately, I had packed enough stoma supplies as getting more would have been impossible. I did run out of some of my medications as we were away longer than expected, but this was unavoidable. I don't think anyone, regardless of how careful they are, packs for a holiday with a global pandemic in mind!

We are grateful that we achieved our main objective in seeing our family in New Zealand, and were so lucky we had no virus on board. Also we managed to visit a lot of places we hadn't been to before. It was certainly a trip we will never forget! ■



We have added a travel section to the Covid-19 information page on our website. This has all the latest travel advice from the government and major UK airports <http://www.colostomyuk.org/covid19/> Please make sure you check the new guidelines before travelling: at the airport, with your airline and for your destination.

Supporting and empowering you

Colostomy
UK

Travel Advice

Having a stoma should not prevent you from travelling at home or abroad

www.colostomyuk.org

Stoma helpline:

0800 328 4257

24/7

Are you thinking about travelling? If so, then remember, **Colostomy UK** have volunteers who have travelled extensively to most parts of the world, using all modes of transport and would be happy to share their experiences with you. Call our Stoma helpline on: **0800 328 4257**, to arrange.

We also produce a booklet: *Travel Advice*. You can download it free from our website. Alternatively call us: **0118 939 1537** or e-mail: info@ColostomyUK.org to request a copy.

Win up to £25,000 with Unity

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

How it works

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

How to join – three easy steps

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

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

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

If you have any queries please call our hotline on

0370 050 9240

Results & Rules can be checked by visiting

www.unitylottery.co.uk

Or by phoning the Unity winners hotline

0370 055 2291

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

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£25 4 digits

5 Prize Entries 3 digits
in the next draw

1. Your details (please print in block capitals)

Title:	First Name:
Surname:	
Address:	
Postcode:	
Tel:	Mobile:
D.O.B.:	If you would like to receive correspondence via email, please tick here <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 = Total Payable
	<input type="checkbox"/> Every 13 wks	£13	
	<input type="checkbox"/> Every 26 wks	£26	
	<input type="checkbox"/> Every 52 wks	£52	

3. Select your Payment method

<input type="checkbox"/> Payment by Cheque	<input type="checkbox"/> I enclose a Cheque made payable to Unity (minimum payment £13)
<input type="checkbox"/> Direct Debit	Please fill in the form and return to Unity Name and full postal address of your Bank or Building Society.
To: The Manager: Bank/Building Society	
Address:	
Postcode:	
Name(s) of Account Holder(s)	
Branch Sort Code:	
Bank/Building Society account number	
Banks and Building Societies may not accept Direct Debit instructions for some types of accounts.	
unity Instruction to your Bank or Building Society to pay by Direct Debit	
Service User Number Reference: 4 2 1 1 0 2	
Instruction to your Bank or Building Society Please pay Unity from the account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this instruction may remain with Unity and, if so, details will be passed electronically to my Bank/Building Society.	
Signature:	Date:

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

Signature:	Date:
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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.

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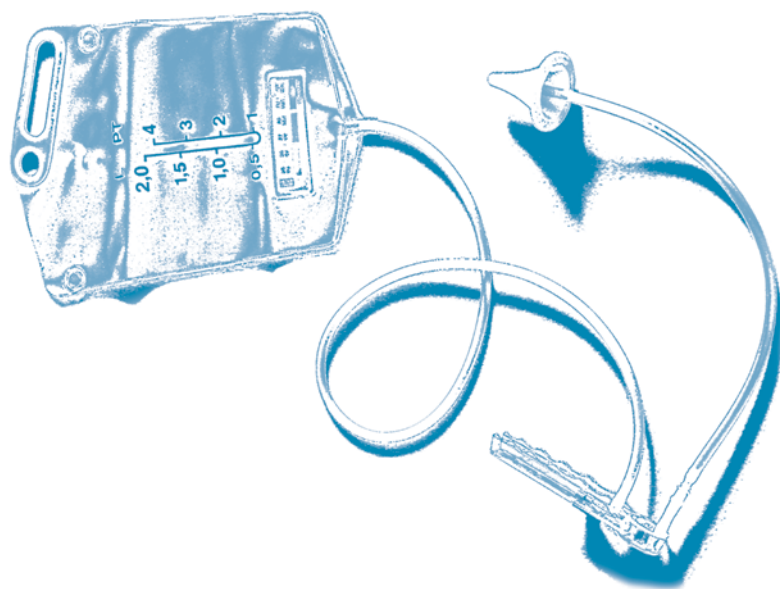
For office use only:

T59

Irrigation and you

Do you irrigate? If you would like to try colostomy irrigation, first contact your stoma care nurse to see if this would be a suitable stoma management option for you. If you get the go ahead they will arrange a time to teach you. For more information see the **Colostomy UK** website or order our *Colostomy Irrigation and You* DVD using the form on page 23.

If you have any questions, comments or experiences of irrigation you'd like to share please write to me at **Colostomy UK** or send an e-mail to: Richard.Biddle@ColostomyUK.org



In the spring edition of *Tidings*, some of our volunteers who irrigate kindly contributed their 'top tips' for irrigating. They imparted words of wisdom to absolute beginners, in particular stressing the need for patience and perseverance in the early months. They also gave some invaluable advice for those who are competent at irrigating but perhaps contemplating their first holiday away from home since starting. This time round, we complete the picture with the top ten tips from Wendy Osborne, who is a Clinical Nurse Specialist in Stoma Care.

Top ten hints for successful colostomy irrigation:

- 1 **Irrigate at a time that works for you** – choose the time that fits in with your daily commitments and bathroom availability.
- 2 **Be prepared** – have all your equipment ready, including what you wish to read/watch/do, after you have inserted the water and the irrigation 'evacuation' is taking place – this is your bathroom routine and 'your time' – nothing strenuous!
- 3 **Sitting comfortably** – the irrigation procedure may take up to 45mins. If you are sitting on the toilet for this time, ensure your bathroom is warm and maybe have a cushion to position behind you. If you have room in the bathroom for a chair next to the toilet, the irrigation sleeve is often long enough to reach down the toilet.
- 4 **Water reservoir:**
 - a Temperature is key – not too hot and not too cold to avoid shocking the bowel. We advise 'tepid' body temperature (37°C), just like the baby's bath water.
 - b Height of the reservoir – when inserting the water, the bottom of the irrigation water bag should be above your shoulder height when you are sitting. A good quality suctioned hook available from any DIY store works well and is transportable.
- 5 **Reduce the wind** – run the water through to the end of the cone before you insert the cone into your stoma – this avoids inserting extra air into the bowel.
- 6 **Be relaxed** – tense muscles in your body, leads to a tense colon. This can impact on how effectively the water can be inserted, the movement of the bowel and evacuation of the contents. Think about what relaxes you – music, knitting, sudoku, watching/playing something on a screen...
- 7 **Don't rush the procedure:**
 - a Slowly insert the water – 10–15 minutes gives your bowel time for the water to reach up into the colon. You are pushing water against the flow.
 - b Manage the flow of the water into the bowel – regulate for a slow steady flow of water. If the flow stops, manoeuvre the cone to change direction of the flow of water as it may be restricted by the side wall of the colon.

CONTINUED ON PAGE 35, COLUMN 1

WHY join us?

As a registered supporter of **Colostomy UK** you will receive a welcome pack full of useful information.

Each quarter you will also receive a copy of this award winning magazine called *Tidings*, and much more...

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

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

www.ColostomyUK.org/join-us/



CONTINUED FROM PAGE 33, COLUMN 2

- c Give the bowel time to evacuate the water and bowel contents. Due to the wave like contractions of the bowel (peristalsis) the evacuation will not come out in one rush. A series of movements will need to occur to propel and empty the bowel.
- 8 **The bowel likes routine** – when you first start to irrigate, the bowel needs to adapt and be ‘trained’ to a new routine. This can take a couple of months. However, irrigating at the same time of day can be really beneficial.
- 9 **Know your body** – once an established irrigator, you will find the output of the irrigation varies on different days – this is normal. If you find you are experiencing breakthrough in between irrigations contact your stoma nurse to talk through your routine and the volume of water used may need to be adapted.
- 10 **Troubleshooting** – there may be concerns or worries at any time; you are not alone, speak to your stoma nurse, or contact **Colostomy UK** for advice.



Wendy Osborne
(RGN; MSc Advanced Nursing Practice)
Clinical Nurse Specialist in Stoma Care;
Clinical Lead – Coloplast Ltd

Supporting and empowering you **Colostomy UK**

Colostomy irrigation:
An introduction
www.ColostomyUK.org

Stoma helpline:
0800 328 4257 **24/7**

Supporting and empowering you

Getting help

Are you thinking about irrigation? If so, then remember, **Colostomy UK** have volunteers who irrigate and would be happy to share their experiences with you. Call our stoma helpline on: **0800 328 4257**, to arrange.

We also produce a booklet: *Colostomy Irrigation: An Introduction*. You can download it free from our website. Alternatively call us: **0118 939 1537** or e-mail: info@ColostomyUK.org to request a copy.

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



Fundraising



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Your letters and e-mails

Ed's note: With the recent spells of nice weather and gradual easing of lockdown restrictions, I was bracing myself for an empty mailbox. Thankfully this wasn't the case. As you will see below people corresponded on a varied range of matters. We also received a crossword, with clues all based around the last edition of *Tidings*. You will find the answers to these at the bottom of the page. The **Colostomy UK** team had some fun trying to complete it. If you do too, then please let me know, as if the occasional crossword or puzzle is something that our readers would like, then we will do our best to deliver!

Dear Editor

Since lockdown I have been going through lots of editions of *Tidings* and something that caught my eye was that people like myself have got a name for our stoma. I call mine 'Donut'. My friend calls his 'Boyzee'. I have picked out from *Tidings* some of the names other people have called theirs including Daisy, Henry, Beryl and Herbert.

Do you think it would be a good idea for other people to name their stoma, just for fun!?

I went in for a bowel cancer operation in August 2016. The operation seemed to go OK, but days later I developed sepsis. I was put in an induced coma for 10 days in critical care, which is when I had my stoma. I spent seven weeks in hospital and then was sent to a nursing home, for another six weeks. I was away from home for 13 weeks in total. The nursing home I went to was Uplands Westcliffe-on-Sea, Essex. I can't praise them enough, they made me well again, so I could start looking forward to life again.

My name is David Spalding Smith. Before I retired everybody at work called me David SS, as there were at least five Davids that worked there. By the way, I am now 75 and looking forward to 6 June this year as we will be celebrating our Golden Wedding – fingers crossed, with my health and lockdown pending!

Hope everyone stays safe in the current situation we find ourselves in.

Yours

David Spalding Smith

Ed's note: David makes an interesting observation about the naming of stomas. It's something I have wondered about too... perhaps giving your stoma a name, makes it easier to talk about? Maybe there is a future article about this! Readers will also be pleased to know that David's 50th Wedding Anniversary went well. Covid-19 might have put a stop to a big party, but he and his wife were still able to enjoy a 'lockdown' meal together along with a glass of wine and a couple of glasses of beer!

Dear Editor

As a member of a large support group for ostomates the realisation that we were going to enter a lockdown to protect us all from the

coronavirus made us very concerned for the order and delivery of our stoma supplies.

I have kept in touch with some members since we have no longer been able to meet and I am delighted to learn that all of us have been well served by our stoma supply companies. Not only have they kept us well supplied, they are also sending out introductions to their new products and inviting us to try them.

In *Tidings*, I note that their adverts are giving us such heart-warming advice and encouraging us to contact their help lines. It seems that the coronavirus has brought us good and positive support from the manufacturers and the delivery companies.

My order has been promptly dealt with by my surgery, and forwarded to the stoma company, the company has contacted me to say "my delivery is on its way" and the box of supplies is delivered keeping the social distancing, efficiently and on-time.

Thank you
Mrs O

Ed's note: I know that many people were worried that the coronavirus might interrupt the normal supply of stoma products. At **Colostomy UK** our sense is that these fears have not been realised; a view supported by this letter.

Dear Tidings

I have been a colostomate for over 20 years and I have always been delighted to receive copies of **Colostomy UK's** *Tidings*. I have watched it change from a few sheets of printed paper to a sophisticated well written glossy magazine. The outside and inside pages may have changed in appearance but the contents have remained as informative and as valuable as in the early days of my learning to live with a colostomy.

I am writing to praise the latest edition of *Tidings*. Congratulations on such a hard-hitting front cover. What an impact on seeing Covid-19 "up-front" as part of our everyday ostomy lives.

It was a pleasure to read the Editor's introduction along with Ms Herbert and Ms Lang writing about all the support available from the staff and volunteers of the charity; just what we needed in these difficult times. Ian Daniels summed up some of our anxieties – where and when do we get to see a consultant or receive treatment for our bowel problems. I was reassured to know that

support will always be there for us and will be led by those who want to give us our life back.

Reading the Real Life Stories of Rachel, Keely, Melvyn and Jackie, I was full of admiration to realise what determination and courage led them all to regain the very best quality of their lives. What shines through this particular edition of *Tidings* is the realisation that we can all get through the bad days, weeks and months of pain and uncertainty and the dread of contacting Covid-19 that

might affect us as we might be classed as having underlying health conditions.

Well done to all those who work on the magazine and to the contributors who are willing to tell their stories so that we may be inspired by their determination to live their life to the full. **BA**

Ed's note: This is just one of many positive letters and comments we received about the summer edition. The whole *Tidings* team were thrilled by this. Thanks also to our contributors.



We look forward to hearing from you, our readers:

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

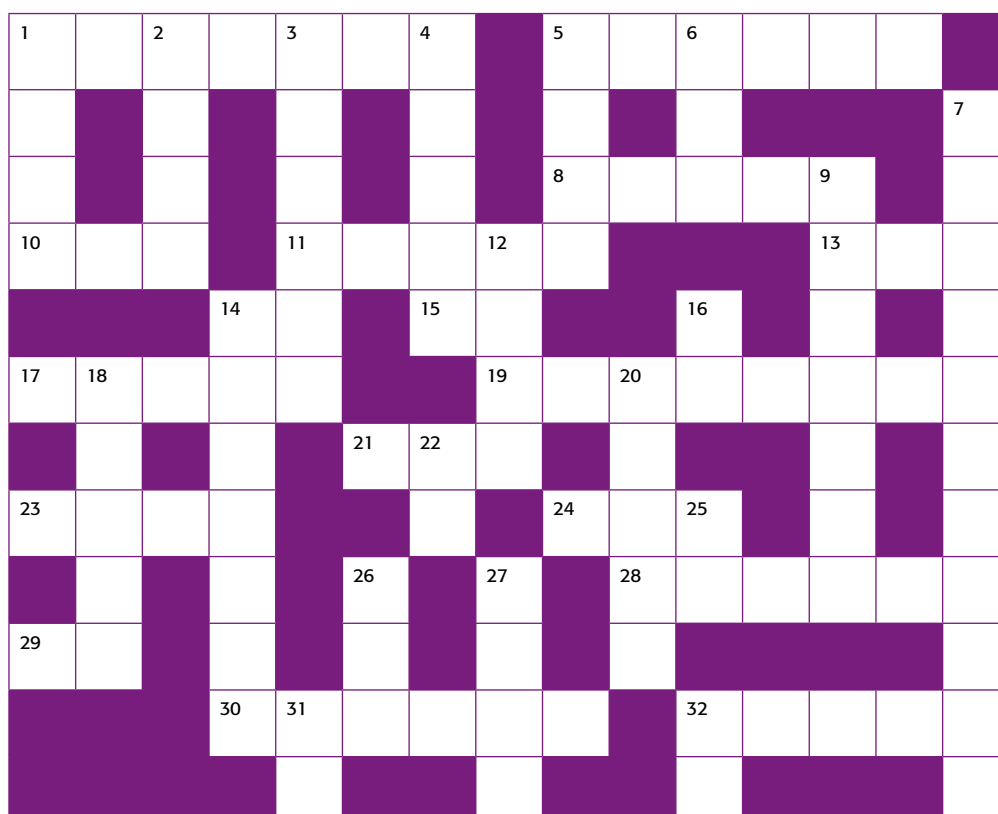
Write a letter to: **The Editor, Colostomy UK,
Enterprise House, 95 London Street,
Reading, RG1 4QA**

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.

Ed's note: I would like to say thank you to Dave Smart for suggesting and putting together the crossword below. The answers to most of clues can be found in the last edition of *Tidings*. Good luck!

Clues across

- 1 It's under your nose
- 5 Our own RB
- 8 **Colostomy UK's** chairperson
- 10 First day of the weekend
- 11 Amanda sans A
- 13 And boy
- 14 Di dah
- 15 Little Simon
- 17 Dear nurse
- 19 Circumference security
- 21 as 10 across
- 23 North of the border
- 24 Not in
- 28 We all give them a name
- 29 Technical info
- 30 Posh pub food
- 32 Semi



Clues down

- 1 BOTS
- 2 A healthy one
- 3 He also agreed
- 4 Swanley group
- 5 Volunteers manager
- 6 Mr Daniels
- 7 Good works
- 9 Slow down
- 12 Balanced
- 14 Blood page 12
- 16 You and
- 18 Covered by WAMS
- 20 Support
- 22 The fourth emergency service
- 25 In the Isle of Man since 1902
- 26 Help
- 27 Barrier cream wanted
- 31 As 22 down
- 32 Cubic capacity

Answers

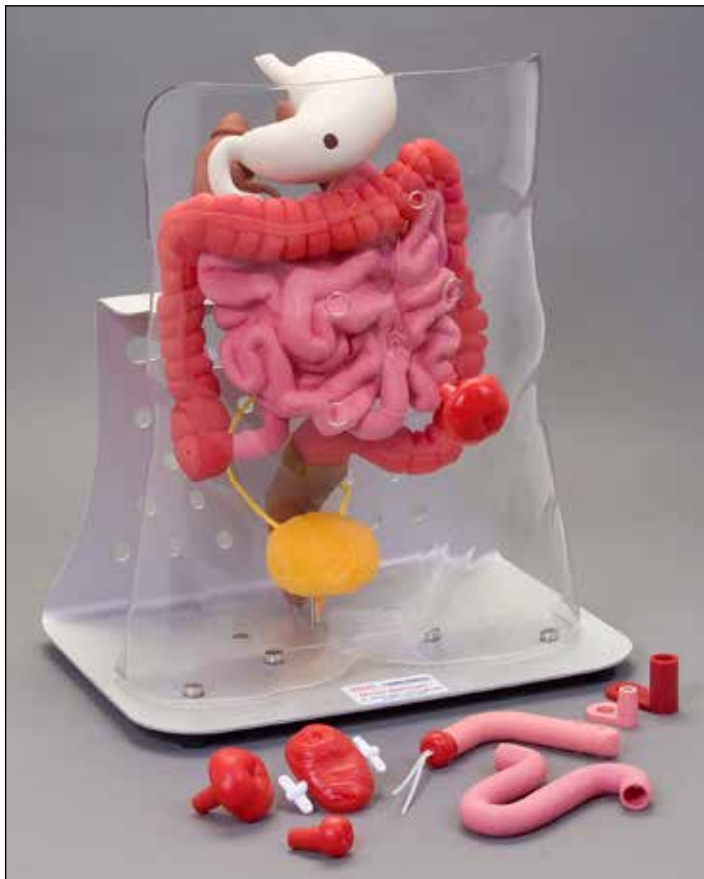
Across: 1 Tidings; 5 Editor; 8 Manda; 10 Sat; 11 Manda; 13 Man; 14 La; 15 Si; 17 Karen; 19 Extender; 21 Sat; 23 Scot; 24 Out; 28 Stomas; 29 IT; 30 Gastro; 32 Colon.
Down: 1 Turns; 2 Diet; 3 Norman; 4 Swans; 5 Emma; 6 Ian; 7 Fundraising; 9 Imodium; 12 Diet; 14 Letting; 16 Me; 18 Ascot; 20 Truss; 22 AA; 25 TT; 26 SOS; 27 Sore; 31 AA; 32 CC.

Dear nurse

Using Otto[†] & Anatomy Aprons^{††}

as teaching aids for stoma care nurses, students, carers and patients

Bev Whittaker Stoma/Colorectal Nurse Secretary
and her team at Blackpool Teaching Hospitals



[†]Otto



^{††}Anatomy Apron

It is widely recognised that people learn in different ways. This is evident in a variety of settings and is something we take into consideration when teaching about stoma care and colorectal cancer conditions. Historically we have had two main teaching streams, each of which requires varying levels of information, advice and support:

- ❖ Nursing students, healthcare assistants and ward nurses
- ❖ Patients

For the first group, it is important to provide up-to-date, evidence-based information to inform their practice, enhance and improve

patient care, and widen their knowledge base. We do this using a lecture theatre-based course that we run at least twice a year, consisting of a PowerPoint presentation interspersed with practical handling of stoma pouches and accessories, with opportunities to cut out pouches and fit them to a pretend stoma. The feedback from these sessions always states that the practical portion is of great value and instils confidence. We intend to introduce Otto and the Anatomy Aprons to our teaching sessions over the next few months. We feel confident that this will enhance the learning opportunities for nurses, providing the all-important visualisation needed for some, and prevent the droopy eyelids and nodding heads of the lecture theatre!

Teaching sessions for our patients comprise of two main elements. Firstly, pre-operative diagnosis counselling in preparation for major colorectal surgery (which often involves the formation of a temporary or permanent stoma). Secondly, following surgery, we teach patients daily in the practicalities of stoma care. This section of teaching is usually the most useful because the visualisation and reality finally come together.

Pre-operatively the introduction of the models has had a huge impact on patient understanding of areas of disease, surgeries and potential results, and the possible side effects of complications. They have helped to underpin the surgeon's explanations and rationale for operating. A number of surgeons have commented on how useful the model is and so beneficial to the whole team.



Otto in use during a patient consultation

Recently, the pre-operative counselling sessions for patients undergoing stoma formation have been altered somewhat. Covid-19 restrictions have led to these sessions being done mainly by telephone. In view of the impact Covid-19 has had on healthcare this year, there will no doubt be future changes made to the systems in place for patients to be reviewed, educated, counselled etc. Going forward, the plans of our team as a whole

will most certainly feature "virtual clinics" and the wider use of technology, thus ending the requirement for the patients to always attend face-to-face appointments/discussions.

The colorectal team at Blackpool Teaching Hospitals purchased the Otto model and Anatomy Apron just before the Covid-19 pandemic, with a view to using them as face-to-face teaching aids. However, going forward, we know they will work well in a virtual environment too. The various options they have for demonstration, will be pivotal to improving the understanding, visualisation and acceptance of potentially life altering surgeries. We hope that this will enable patients to make the transition to "life with a stoma" easier. As well as improving the current systems for contact with patients, the Otto model will be introduced to planned training/teaching sessions (whether these be face-to-face or virtual) with nursing/care homes, district nurses and GP practice nurses, GP's, social workers, teachers and carers. The stoma team at Blackpool Teaching Hospitals provide support to our community colleagues whenever it is requested, and it is hoped that with the help of this visual aid, the understanding of a patient's stoma experience will benefit carers and patients alike. ■



Sister Barron demonstrating the bowel/stoma with Sister Gregson using the Anatomy Apron

Get your own training aids

Otto Ostomy and the **Anatomy Apron** are obtainable from Colostomy UK. You can place your order on our website by going to: <https://colostomyuk.bigcartel.com/> or you can send in your purchase orders to the office. The cost is for sending to the UK only (for overseas orders please contact us at: info@ColostomyUK.org) and includes VAT, post and packing.



Otto Ostomy

Otto Ostomy Anatomy Model is an excellent teaching resource. Using a simple colour-coding system for the various organs, Otto can help patients better understand the workings of their digestive system and urinary tract. An end or loop colostomy and ileostomy can be demonstrated, along with a urostomy and gastrostomy tube replacement.

Price correct at the time of going to press. **£1,999.00**



Parts included:

- Small intestine segment
- Ileostomy loop adaptor
- Colostomy loop adaptor
- Ileal conduit

Stomas:

- 3" Diameter stoma
- Loop without rod
- Double barrel stoma
- Oval stoma

- Granuloma stoma
- Necrotic stoma
- Mushroom stoma
- Prolapsed stoma
- Ischemic stoma
- Flush stoma
- In-skin fold stoma
- Parastomal hernia stoma
- Mucocutaneous separation stoma
- Recessed stoma



Anatomy Apron

Our anatomy aprons are a fantastic teaching tool for educating people about the various kinds of stomas.

Aprons can help explain a variety of different surgical procedures including colostomy, loop colostomy, transverse colostomy, ileostomy, colectomy and hemicolectomy.

Price correct at the time of going to press. **£156.00**

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 the last edition of *Tidings* we gave some great hints and tips and highlighted links to activities that could keep you both physically and mentally active during the coronavirus lockdown.

With us still unable to deliver our normal community Active Ostomates sessions through stoma support groups, and a growing awareness that organised activities may not return for some time, in April **Colostomy UK** introduced a new initiative 'Active Ostomates: At Home'.

Active Ostomates: At Home



Our 'Active Ostomates: At Home' initiative takes some of our great community activities including chair yoga and art and puts some online. It also introduces new online Mindfulness and Meditation workshops and Visual Art sessions.

Mindfulness and Meditation workshops last for 30 minutes and are suitable for complete beginners as well as regular meditators. Led by Sophie, the classes are fully guided and aim to support you to find calm and ease in your life, no matter what's going on. Breathing techniques, body relaxation and mindfulness will be taught in these classes.

Classes are accessible, with no prior experience in meditation required.

Virtual Art sessions last for 40 minutes and involve taking part in simple step-by-step drawing exercises using pencil and paper and led by artist Louise Bradley. You will look at proportion and

expression and gain confidence in drawing faces from photographs provided on screen.

These sessions will guide you in basic drawing skills and techniques that you can use to improve your work and use outside of class.

Suitable for all levels from complete beginners to experts!

Here's some of the feedback we've had so far:

"I really enjoyed the session yesterday. Louise was very clear and I thought the pace was just right. I found some of the techniques she was showing us really helpful. I've just taken up sketching in the last few months, so still lots to learn but finding it quite therapeutic."

"I was thrilled to take part in these lessons. In lockdown it has given me time for myself. Practising in between lessons will give me a sense of purpose. I really enjoyed the lesson and as well as learning about drawing I learned about Zoom too. A very useful skill for the current time. Louise explained and demonstrated well, giving us enough time to do the tasks."

To find out more about **Active Ostomates: At Home** including the latest dates for our online Mindfulness and Meditation and Virtual art sessions visit:

<http://www.ColostomyUK.org/active-ostomates/>

Anyone can join these sessions. All you will need is an internet connection and a smartphone, computer or tablet.

Our **Chair Yoga** sessions have been growing in popularity since 2016. We're now delighted to also be able to offer a series of online videos so you can practise in your own time at home.

Each video focuses on a different part of the body including arms and hands, neck and shoulders, hips, legs, feet and side body.

The yoga exercises are all easy to follow and can be repeated as often as you like. All you need is a chair!

You can watch our series of Chair Yoga videos through our website <http://www.ColostomyUK.org/active-ostomates/active-ostomates-at-home-chair-yoga/>

#ActiveOstomates

Colostomy UK's Lockdown Memory Quilt

Recent visitors to our website may have come across our 'Memory Quilt'. We started this in May as a way to record ostomates' experiences of living with a stoma during the coronavirus lockdown. We'd love you to take part!

Your finished square needs to be 20cm by 20cm, so please use a piece of fabric 22cm by 22cm to enable us to sew all the squares together. You can use any fabric, from a piece of clothing to a tea towel or even bed linen. When it comes to decorating your square, anything goes: pens, photo transfer, appliqué or embroidery. It's also fine to include a word, message or picture that captures what lockdown has been like for you.

As you can see from the photos, we've already received lots of squares, with a whole variety of designs. The finished quilt will be auctioned to raise funds for **Colostomy UK**.

Please send your finished square by the end of October by post to: **Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA.**

We also want to feature the quilt and individual squares on social media. If you don't want us to share a picture of your square in this way, then please let us know.

Please see below some of the amazing patches we have already received:



Every Mind Matters



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/>

Sport and Fitness After Stoma Surgery



Colostomy UK's very own *Sport and Fitness After Stoma Surgery* booklet includes a series of exercises that encourage core strength and can be repeated daily. Each of them works deeply, increasing the strength of your back and stomach muscles, helping to reduce back and posture problems as well as the risk of post-operative hernias. They can be performed on the bed, lying on a thick mat so that your spine is gently cushioned, or sitting on a chair. Some can even be done while you are watching the television!

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.

TEAM COLOSTOMY UK TRAINING VEST

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

Tight fitting order one size up.

£28
incl P&P

S	M	L	XL
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



TEAM COLOSTOMY UK BEANIE HAT



100% soft touch acrylic.
Features: embroidered **Team Colostomy UK** logo on front. One size fits all.

£11
incl P&P



Kit and Merchandise

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:

www.ColostomyUK.bigcartel.com

SIZE GUIDELINES

All clothing items are a standard fit unless stated.

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

#UPTHEPURPS T-SHIRT



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

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

£18
incl P&P

S	M	L	XL	XXL
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

TEAM COLOSTOMY UK HOODED SWEATSHIRT

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

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

£35
incl P&P

Purple

S	M	L	XL	XXL
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Charcoal

S	M	L	XL	XXL
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



TEAM COLOSTOMY UK TRAINING SHIRT

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



£33.49
incl P&P

S	M	L	XL	XXL
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Please send me the above marked items.
I enclose a cheque for:

£

Payable to: **Colostomy UK**

All products sold individually and prices are per item and inclusive of VAT & P&P to UK and NI only. Please allow 28 days for delivery.

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Name:

Address:

Telephone:

Postcode:

Email:

SLEEVE LOGO T-SHIRT

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

Available in Sorbet
100% Soft spun cotton.

£14.50
incl P&P

S	M	L	XL	XXL
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



COLOSTOMY UK T-SHIRT

Available in both purple and pink.

100% Heavy duty cotton.

Purple T-shirt

S	M	L	XL	XXL
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Pink T-shirt

S	M	L	XL	XXL
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

£14.50
incl P&P



You can shop online: www.ColostomyUK.bigcartel.com or mail your completed form to:
Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire RG1 4QA

T59



Victoria's story

Victoria Kemmish

Ed's note: As you will have read in Glen Saffery's article on page 15, an international research project has recently begun to better understand diverticular disease. As readers familiar with the disease will know, the symptoms are not just unpleasant and frightening but their onset can be rapid and unexpected. This is illustrated well by the story below, which coincidentally arrived in the editor's 'inbox' at almost the same time as our contribution from the Bowel Disease Research Foundation.

In August 2019 I started to get severe pains in my tummy. Thinking that there were people probably more sick than me and not really sure that I was an appropriate case for Accident and Emergency (A&E), I decided to book to see my GP instead. My GP examined me and sent me for blood tests and an ultrasound. Although the latter came back clear, the blood tests showed I had an infection and so I was prescribed antibiotics. These did the trick and a follow-up blood test showed I was clear of infection. At the time, I thought nothing more of this episode and was quickly back at work and the hectic nature of life more generally!

However, a few months later, on 12 October, I started to feel very unwell again. I was so unwell I was sent home from work. As soon as I got home, I went straight to bed, which those who know me well, will tell you is very unlike me. I wanted to sleep, but I couldn't because the pain was so bad. In the end I couldn't stand it any longer and so went to the on-call doctor, who immediately sent me to A&E as I had a high temperature and my heart was beating fast (both of which are signs of infection).

In A&E I had to endure a long wait. Blood tests were done and a urine sample was taken. I was also put on IV antibiotics. I was then sent home at 4:30am with antibiotics. I was still in pain, so I went to see my GP who prescribed some strong painkillers. Unfortunately, there was no improvement, in fact, my symptoms got worse. A few days after my visit to A&E I woke up vomiting. As I hadn't really eaten much since returning home from the hospital, all that was coming out was water. I knew that this wasn't a good sign. As it was a Saturday I had no choice but to go back to A&E. Luckily it wasn't busy. I was admitted immediately and had a CT scan. This showed that I had diverticulitis.

At the time, diverticulitis wasn't something I knew much about. But this potentially life-threatening disease had perforated my bowel and I also had sepsis, as my body went into overdrive trying

to fight infection. Initially, attempts were made to treat me with IV antibiotics, but sadly these didn't work. The consultant told me that I would therefore need surgery and that I would have a stoma for a while. I went to theatre without further delay, where the part of my bowel with diverticula was removed. A stoma was necessary in order to give my remaining bowel time to heal.

In a short space of time, I had been confronted with a diagnosis about a disease I knew little about and surgery which left me with a stoma. I knew what a stoma was, but nothing more than that! I had a lot to learn. I read lots and the stoma nurses were really helpful, but it was difficult having to take on board so much so quickly. This wasn't helped of course by the mental and physical toll of the surgery and what I had been through in just a few months. After the surgery I was very sore. I had lines going into my neck and a tube up my nose and down my throat. I found these extra attachments to me and all the machines around me very disconcerting. As I am sure is very common, I felt generally very sorry for myself. I couldn't eat for 12 days' post-op, but when I finally did, that first soup and yoghurt tasted amazing.

Once home, I started to adapt to life with a stoma. Just like other people I have read about in *Tidings*, I have my good and bad days. When I have my bad days I remind myself that my stoma saved my life. I am also lucky because I have the option of a reversal. I recently went for a colonoscopy which, though showing some diverticula still, revealed that my bowel has healed well. I have diverticula disease in my family, but I never realised just how serious it could be. Looking back, I had a feeling that something wasn't right. But as the tests had shown nothing was wrong I thought everything must be fine. I now realise I should have persisted, articulated my concerns and asked for more tests. In hindsight, it shows you should listen to your body, as you know your body best. My advice to anyone reading this, is if you are ever worried about anything, you should go to your GP or the hospital! ■



Charting my stoma journey th



Picture 3: Me standing on a rock



Picture 4: Nature around me



Picture 5:
A simpler style

Ed's note: In the last edition of *Tidings*, Gillian Cowell wrote about the therapeutic value inspired to start painting and drawing – either for pleasure or for a way to express how you feel during sessions that Colostomy UK run. All pictures are numbered going clockwise from bottom left.

My journey with a stoma started in September 2018 when I had a colonoscopy and a growth was found in the lower bowel. Following a biopsy and MRI/CT scans this was confirmed to be bowel cancer, with secondary cancer in the liver.

As anyone who has had a similar diagnosis will know, this hits you like someone punching you in the stomach. It was hard for both me and my wife to take in at first, it was like something unreal. I have been drawing and painting for more than 30 years. I painted *The hope* (Picture 1) as a response to how I felt on hearing the news. At this point neither of us were sure if I would get to Christmas. Although the diagnosis looked bad, the hope that I would get through this experience remained.

At this point, still not knowing what the future would hold, I painted a picture of Bamburgh Castle for my wife (Picture 2), as it is one of her favourite places.

As a Christian, the hope that I would come through this was sustained by my faith in God. My family, church and friends around the world also started praying for my situation and healing. Many of them felt it was important that I continued painting and drawing through this journey. This led to the next picture, of me standing on a rock (Picture 3). The rock symbolises my faith in God and that through this he would enable me to beat this cancer.

In October we talked to the bowel surgeon who confirmed that the cancer was only in the final section of my bowel and that there was secondary cancer in the liver. He considered that both were treatable. My treatment plan would include two major operations and periods of chemotherapy.

During this waiting time my condition was deteriorating and I was finding it harder to draw and paint, so I adopted a simpler style. It is amazing how even when you think you cannot do anything, using creativity can help you keep going. I found myself looking at the work of Kandinsky and nature around me. The following paintings came out of this period in my journey (Pictures 4 and 5).

They tried a stent to alleviate my bowel condition but this only made my situation worse, so on 20 December I had bowel surgery, which resulted in a stoma. The extent of bowel removed meant the stoma would be permanent.

Once into a routine, life with a stoma seemed to be fairly easy at first. During this period while I recovered from the bowel surgery, I was involved in three projects. The first was to illustrate a children's book for a friend about a mouse who meets a rabbit (Picture 6). The second was to paint and organise pictures for a café at our church (Picture 7). The third was to organise an art exhibition in our church for the Lincolnshire Open Churches' weekend (Picture 8).

Things continued smoothly, until I started my first block of chemotherapy. Anyone who has had chemo will know it can be very unpredictable. My chemo cycle involved a daytime infusion at the hospital, followed by two weeks of tablets and then a week off prior to starting the next cycle. This all sounded fairly straight forward, and we planned out how the proposed four cycles would impact our diary. Unfortunately, this did not work out to this plan.



Picture 2: Bamburgh Castle



Picture 1: The hope

through drawing and painting

John Blundell



Picture 6: Illustration for book



Picture 7: Painting for the café

of 'crafting'. What follows is a great example of this! If, after reading John's story, you are feeling – then don't forget to check our website for details of the Creative Minds Arts ft.

The first problem was the infusion was so painful in the vein in my arm. This is apparently a common side effect of bowel cancer chemo. Therefore, it was decided to insert a pic line in my arm to enable the chemo to be administered directly rather than through a vein. This reduced the pain in future chemo sessions but required a weekly visit to the hospital to have it cleaned and checked. This went on for about nine months, which became another tiring aspect of the journey.

The next thing was that my stoma reacted to the chemo. The first thing to happen was that it dramatically changed size and shape. It started to get swollen and longer and would move back and forth on a daily basis. I believe this is called "telescoping". As you can imagine this was very disconcerting when it first occurred. Then I found it would bleed very easily, which again was not a pleasant experience. This led to several phone calls and visits to the stoma nurses at the hospital, all of whom were really supportive and helpful.

The worst was at the end of the third cycle when my white blood count was so low that they could not give me cycle four. At the same time the stoma reacted badly and changed colour to a yellow brown and became even more swollen and was about 10–13cm long. On seeing a stoma nurse I was admitted to hospital and spent three days there while they assessed the situation. With rest it started to calm down. Although still larger in size the pinky colour returned, much to everyone's relief, not least my own. During this stay in hospital I had a CT scan to check all was working correctly with my stoma, which was found to be so. The unexpected result was that the tumour in my liver had shrunk by 40%,

which I was told couldn't happen with the chemo. Eventually it was decided to let me go home. I was told to rest as much as possible and that the fourth cycle would be abandoned.

Another problem was finding a stoma bag that would accommodate this changing stoma size and shape. So this was a time when I tried several different designs of bag. Up to this point I had not realised just how many different designs there were available. Eventually a suitable bag for my condition was found. I learnt that you need to persevere and talk to the experts.

This period was a very difficult time to keep drawing and painting, so I just did small pieces. They tended to be based on geometrical shapes (Pictures 9 and 10).

As before creativity was one of the things that helped me through this period.

It was decided to undertake the liver operation as soon as I was fit and recovered sufficiently from the effects of the chemo. By the time I went for liver surgery my stoma was still suffering but I had learnt how to manage it. The stoma had just started to recover and was now more normal looking most of the time, when they decided it was time for more chemo. I had another three cycles, which caused all the same problems I had previously with my stoma but now they were manageable. Fortunately, this time it did not require a stay in hospital as they reduced the dosage.

My final chemo session ended at Christmas 2019 and in early January I was given the all clear from cancer. As I started to recover from this last chemo session I found it was possible to start painting my favourite subject – the sea (Picture 11). ■



Picture 8: Lincolnshire Open Churches' submission



Picture 9: Difficult period 1



Picture 10: Difficult period 2



Picture 11: The sea – post-chemo

Colostomy UK: focus on fundraising



Giovanni Cinque
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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.

Can you help us 'Be the difference'?

The support Colostomy UK offers is needed more than ever now. As the effects of lockdown have made their mark, so more and more stories of loneliness and isolation have appeared in the media. At Colostomy UK we have seen growing demand for our **Stoma Helpline** and **Instant Messaging** service. We also know from the many letters and e-mails we received after the summer edition of *Tidings* just how vital the support and information it contains has been to ostomates and their family members and friends too.

We are proud of the positive difference these services make to the lives of thousands of people.

Can you help us continue to 'Be the difference' by making a regular donation to Colostomy UK?

Regular donations help us to better plan for the future by giving us more of an idea how much income we will have each year. This means we can continue to develop new services where there is a need for them (like our recently launched **Instant Messaging**), and further develop our existing offerings such as our 24-hour **Stoma Helpline**.

You can set up a standing order using the form on page 49 or a direct debit through Just Giving or Virgin Money Giving by visiting our website <http://www.ColostomyUK.org/how-to-donate/>

Thank you in advance for your support.

Brilliant Birthdays!

A Birthday fundraising page on Facebook is an easy way to make a real difference for us, especially at this time, and something that everyone can do. For more details visit: www.facebook.com/fund/colostomyuk

Thank you to the following who are just some of the people who have kindly supported us with Facebook fundraising pages recently:

Jessica Sparshott, Victoria Young, Sarah Peck, Liam Manning, Alan Raymond, Heather Harper, Margaret Shearer, Rea Anne Finley, Janey Hane, Barbara Harrison, Graham Wells, Melanie Clayson, Lara Rufus, Clare Craven.

Rising to the challenge!



The last weekend of April saw thousands of people across the country take part in activities in their homes or outside (observing social distancing) as part of the 2.6 Challenge to raise much needed funds for charities including Colostomy UK.

The 2.6 Challenge was the brainchild of the London Marathon's organisers. Forced to cancel this year's event, they wanted to come up with an alternative, to help charities recoup lost income. As you have probably worked out, the '2.6' in the '2.6 Challenge' comes from the 26.6 mile distance of a marathon!

Here at Colostomy UK we were lucky enough to have a team of 'heroes' who, donning their running or walking shirts and shoes, or picking up their musical instruments and paint brushes, raised funds and awareness for us. Thank you to everyone who took part. You managed to raise over £5,000 for Colostomy UK.

Putting the FUN back in fundraising

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

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



Trusts and Foundations

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

Sir Jules Thorn Charitable Trust, Princes Risborough Lodge, Joseph Strong Frazer Charitable Trust, Bartlett Taylor Trust, the Childwick Trust, Rest Harrow Trust, Sir Jules Thorn Charitable Trust.

Have your cake and eat it



When the coronavirus put a stop to our Team Colostomy UK Rugby League game at Chorley Panthers in March we were not only denied a great day of sporting action, but we also lost the chance to sample some of the great treats on offer from the Bikini Baker.

Amazingly though, Chloe (aka the Bikini Baker) decided to hold an online raffle instead and last month managed to raise a brilliant £500 for **Colostomy UK**!

We're really grateful to Chloe for her support.

Raffle update

The last issue included a book of ten tickets to our Annual Prize Draw. Thank you to everyone who has entered so far.

Top prize is **£2,500**, the runner up prize is **£1,000**, and there are also ten third prizes of **£100**.

The last date we can receive entries is **Friday 16 October** so you still have time to enter. If you'd like some more tickets just call us on: **0118 939 1537** or e-mail: **info@ColostomyUK.org**

Legacy

You will have found a copy of our Legacy leaflet inside your copy of *Tidings*.

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

We do understand that considering who to leave a gift to is an important decision so, if after reading the leaflet you have any questions or queries, please don't hesitate to get in touch with us on: **0118 939 1537** or e-mail: **fundraising@ColostomyUK.org**



Help us support the ostomates of today and tomorrow



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

WANTED

POSTAGE STAMPS

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



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

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



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. _____

_____ D D M M Y Y

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

T59

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



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.

Hall3 010000018 Birthday Fundraiser | Date of Publication: September 2020 | Copyright ©2020 Colostomy UK | Registered charity no. 1113471

Photo ID Card

The **ColostomyUK** photo ID card can be useful if challenged when using accessible toilet facilities.

To apply for a Photo ID card, complete the form opposite and return it to **Colostomy UK** for processing with the enclosures listed below:

- A copy of your prescription or delivery note as proof of eligibility
- Passport photo x 1
- Payment – cheque or credit card*

***Note:** Credit card payments can be taken over the telephone if preferred, ensure the above are sent in the post in advance.

Alternatively, the form can be downloaded from our website: www.ColostomyUK.org

Allow maximum of 10-14 days for delivery.

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

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

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

National Key Scheme – Key and photo ID card purchase

Title: _____
 Name: _____
 Address: _____

 Postcode: _____
 Tel: _____
 Email: _____

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

Signature of self or carer: _____



Please **tick** as appropriate:

- ☐ I would like to receive a **key £3.50** (including postage and packing).
- ☐ I would like to receive a **photo ID** card for **£6.50** (including postage and packing) and enclose a passport photograph.

NOTE: Please send a copy of your prescription/recent delivery note as proof of eligibility and make the cheque payable to: **Colostomy UK**.

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

Date: _____ / _____ / 2020 T59

News from support groups across the UK

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

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



Shropshire BOTS (Bums on Tums) in Lockdown

The Bums on Tums Support Group here in Oswestry have not been sitting around feeling sorry for themselves during this surreal time. Oh no.

Instead, they have been very busy doing everything from gardening, painting, making cards, flower arranging and dressmaking, to getting out and about and exercising in the lovely countryside! And, that's not all...members have also been doing quizzes with their grandchildren via the internet, taking part in fusion yoga via an App through the TV and doing puzzles to keep the brain exercised. One member was caught in New Zealand at the outbreak and has still to get home; luckily he has family there. Others have told how nice it is to have their partners home, due to furloughing, and to be able to spend more quality time with them.

Although the group cannot meet up yet, we continue to send out monthly newsletters with any snippets of interest and we are collating a scrapbook of photographs members have sent to show

their achievements. We have concluded that the gardens in these parts must be absolutely beautiful with all the attention they have received! We are very impressed with the things members have found to do to keep busy and amazed at some of their, previously unknown, artistic talents.

However, we have decided it would be prudent to cancel our Open Day in October as we feel that people will still be wary of mixing in large numbers. It would also be very difficult to deal with social distancing. But our Open Day will be back on 7 October 2021 – bigger and better!

To find out more about BOTS contact Irene Constable: **01691 238 357**

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

Stoma care open days

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

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

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

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

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

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

Stoma support groups in your county

Channel Islands

Guernsey

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

Jersey

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

England

Berkshire

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 T: 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
T: 0800 318965
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 764 075
E: 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 01388 818 267
E: rdavison816@gmail.com

Darlington Support Group

Margaret Clothier: T: 0191 333 2184

Durham Stoma Support Group

Lynn Ridley, T: 0191 333 2184

Cornwall

Cornwall & Plymouth Bowel Cancer Support Group

The Secretary: 01872 241 145,
cbcsginfo@gmail.com or W: 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
murphy.rowe781@btopenworld.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)
E: 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

E: devon@iasupport.org

Mid Devon Ostomy Support Group

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

Plymouth & District Bowel Cancer Support Group

Wendy Wilson - Facebook: Plymouth
Bowel Cancer

Dorset

Colostomy Urostomy Pouch Ileostomy
of Dorset - CUPID (Bournemouth)
Beryl Andrews 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
E: 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
E: stepsessex@gmail.com



Hampshire

Replummed stoma support group
www.replummed.me

Solent Ostomates Support Group (S.O.S.)

For information T: 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 E: 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
E: 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,
Treasurer David Christian 07970 220
773, Secretary Maureen Curnow 07989
773 332

Dartford Ostomy Group Support (DOGS)

Tracey or John: 07779 155 846 or
07948 974 350 or
dogs-uk@hotmail.com

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
E 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

Stoma Friends Group Support Dover

Carolyn Fullager: 01304 821 132

SWANS Stoma Support Group -

Swanley

Heather - 07711 445 312
heather601@virginmedia.com

Thanet Stoma Buddies Support Group

Kathy Thornberg 01843 291 825

Tunbridge Wells Stoma Support Group

Cathy Chitty/Mags Donovan
01892 632 323

Lancashire

Kangaroo Klub, Blackpool stoma support group

T: 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
E: 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)

T: 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

For more info please call
01553 775 698, 01553 674 962,
01553 768 271

Norfolk Ostomates Support Group (on Facebook too)

Barbara Harris 01603 417 046 /
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 Minshall: 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 W: <http://www.normandystomagroup.wordpress.com>

Stoma Support Group

Robin Young: 01428 723 255

SUPPORT

Sussex

Brighton & District Support after Stomas (SAS)
Virginia Keefe: 01273 723 775
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
NHS Molineux Support Group
John Burchell 0191 265 1047
Royal Victoria Infirmary Support Group
Stoma care nurse specialist:
0191 282 4116
Sunderland Support Group
Michele Downey 07704 949 30
E: 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. E: info@wessex-stoma.co.uk W: 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
E: midyorks.bottomsup@gmail.com
Bradford Stoma Support Group
Lisa Hall 07552 276 747
Dewsbury & District Stoma Support Group
June 07884 003 945 or
E 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
T: 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
E: 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
Domenica Lear 01443 443 053

Swansea

Swansea Ostomy Self Help Group
Glynis Jenkins: 01792 418 245

Colostomy UK literature range

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eMail:
info@ColostomyUK.org

website:
ColostomyUK.org/information



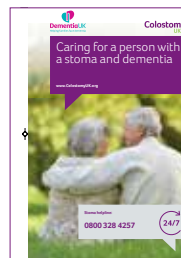
Active Ostomates
Sport and Fitness
after stoma surgery



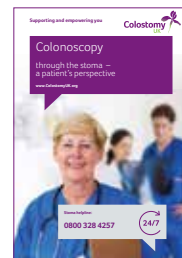
Campaigns &
Projects Flyer



Caring for
Colostomates



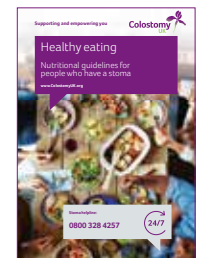
Caring for a person
with a stoma and
dementia



Colonoscopy
through the
stoma



Fundraising
Pack



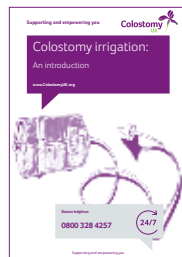
Healthy Eating



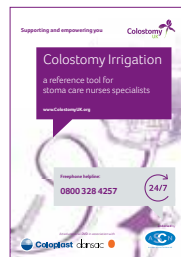
Helpline Cards



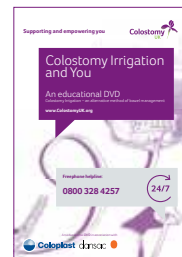
How will a
Colostomy
affect me?



Irrigation
Booklet



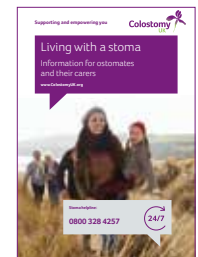
Irrigation DVD
(nurses)



Irrigation DVD
(patients)



Legacy Flyer



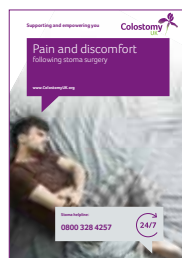
Living with
a stoma



One to One
(join us) Flyer



Ovarian
Cancer and
stomas



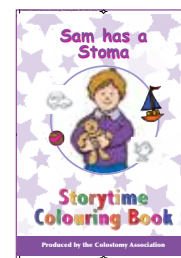
Pain &
Discomfort



Parastomal
Hernias



Rectal
Discharge



Sam has a stoma
(colouring book)



Stoma friendly
toilet guideline
and stickers



Stoma
Reversal



Tidings
Magazine



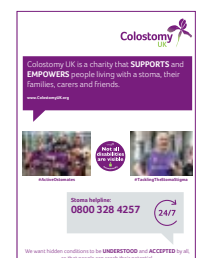
Travel Advice



Travel
Certificate



Tri-Charity
Leaflet



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Colostomy

Urostomy

Ileostomy

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