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Welcome to the summer edition of *Tidings*. Before running through what we have in store for you, I have a couple of announcements to make. Firstly, I am delighted to report that Mandi Laing, one of our volunteers and a trustee of **Colostomy UK** since December 2015, has been appointed as our new chairperson. You can read more about Mandi on page 6. Secondly, since the spring we have had a number of changes to the *Tidings* editorial board. Both Sarah and Libby have stepped down, with me taking over the reins. I'm sure that readers will join me in saying a big thank you to both of them for all their hard work. They have successfully managed to enhance the look of our magazine without compromising the quality of its content.

So what's to look forward to in pages ahead? Well, lots! Our real lives stories cover a whole range of issues. With Sandra Willoughby's story we revisit the topic of reversal surgery and learn how she managed to cope when her reversal didn't go to plan. This is followed by an extraordinary story about a great friendship which has developed between two ladies (Lucy and Tracy) via our closed Facebook group. As you'll see when you read it, it's called 'Parallel lives' for good reason. We then hear from Trevor Alexander who talks, amongst other things, about the reality of facing a cancer diagnosis. If you have been a *Tidings* reader for some time, then you'll probably recognise the author of our final story: Rosemary Brierley. For those that don't know, Rosemary is one of our long-serving volunteers and a past editor of *Tidings*. Having been forced to retire early because of illness, Rosemary explains how she found 'writing' helped her to cope with the chronic pain and come to terms with what she had been through. It is an inspirational piece.

This time round, in addition to our usual features (Colostomy UK News, Fundraising, Active ostomates and Irrigation), we are also lucky enough to have a number of articles from experts in their field. Sophie Medlin, who is a dietitian we have worked with for many years, writes about weight gain following stoma surgery and has some very useful advice around understanding and improving one's relationship with food. Tim Smith, who is a partner at Moore Blatch solicitors, has contributed a very informative piece explaining your options in the event that something goes wrong with your treatment. We hope that the firm will be able to contribute further to *Tidings* in the future. We then round matters off by looking at 'Gut Feeling', a support group set up in Leicester by stoma care nurses Michelle Hill and Fliss Nutting, for children and young people with stomas and their parents.

Finally, there's our cover story. Please don't be fall into the trap of thinking this is just about Rugby League. While this is part of the story, it's much more than that. I recommend it as a read. If nothing else you will get hear from Ian Daniels our president and why, speaking as a consultant colorectal surgeon, he wants to encourage ostomates to get active!

Best wishes



Richard
Richard Biddle
Editor,
Writer & Researcher



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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 45 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

Our new Chairperson



We are really pleased to introduce you to Mandi Laing, **Colostomy UK's** new chairperson. This is what Mandi had to say about herself and taking on the role:

I met Henry (my colostomy) just before Christmas 2010, after a two-year period of misdiagnosis and multiple trips to the

GP. What had been diagnosed as piles was actually cancer and my issues with going to the toilet were due to a lemon size tumour slowly closing my rectum down. It wasn't the best Christmas ever, but it was the start of a new phase of my life. Like most people, I did not have a colostomy on my wish list, but by the time I got Henry, he made a

more positive impact on my life than almost anything else (barring getting married and buying my dog!). He gave me my life back, enabling me to be more than 30 seconds from a toilet and reminded me that you're only here once and you should grasp every opportunity you can. I applied for a new job, became a magistrate and got involved with the **Colostomy Association**, now **Colostomy UK**.

I am now the chair of this fantastic charity. I'm energised by the way the charity is changing, the initiatives we are involved in and our great team, from those in the office, through our registered volunteers, to people who offer support and help on our closed Facebook group. Our general manager (Libby) is a force for change and is helping modernise and translate our strategic vision into tangible results. The projects and campaigns we are involved with will deliver positive changes in the ongoing lives of ostomates that complement and continue our more traditional support services, which tend to be weighted towards the early days of being an ostomate.

It is a great honour to be the Chair of **Colostomy UK** and I am confident we will continue to improve the life of ostomates, in new and exciting ways. ■

On the road...

Libby Herbert our general manager was pleased to be invited to attend meetings at Coventry stoma support group (run by Martin Robbins) and Glasgow stoma support group (run by Morag Sinclair). Both

are well run and established groups. When possible, members of the Colostomy UK team are always keen to make visits like this. Libby says that she enjoyed some lively discussions about all things stoma. For her a couple things stood out. Firstly, it was evident that the problem of ostomates facing abuse when they use accessible toilets continues to be experienced up and down the country. As she says, it reinforces the importance of our work in this area, trying to raise public awareness. Secondly, that knowledge about irrigation as a means of stoma management is still patchy amongst ostomates. We are currently rewriting our literature on irrigation, so hopefully this will help spread the word further afield! ■



L-R: Libby Herbert and Martin Robbins



Glasgow stoma support group – 7 May 2019
(Left from the top) Helen, Sharon, Ken, Veronica, Isabel, Pat
(Right from the top) Christine, Bill, Roberta, Jackie, Libby, Linda



Airport update

As you know **Colostomy UK** is heavily involved in advising UK airports as they strive to make air travel easy and accessible for people with hidden conditions. Back in April Cardiff-based Respond Healthcare were asked by Cardiff Airport to provide some stoma awareness training to their security and other customer-facing staff. Knowing about our profile in this area, Respond contacted us and we were pleased to be able to contribute to the day. Libby attended on our behalf, reporting back that three sessions were led and delivered by Alison, one of Respond's stoma care nurses, and that staff at the airport were keen to listen and learn. ■



More opportunities to join the Colostomy UK team

The spring edition advertised for a Finance/ Treasurer trustee to take over from Alfred Levy who is about to retire. Well, we had a fantastic response so thanks to everyone that spread the word. As a result we are now considering a number of strong candidates for the role.

We also have some new exciting opportunities to announce. We are looking for trustees with experience and appropriate qualifications in the following areas: human resources/legal; secretary; fundraising; marketing; healthcare professional.

Please be aware that all are unpaid roles, but expenses associated with the role will be covered.

If you would like further information please contact: Libby Herbert by telephone: **0118 939 1537** or by e-mail: libby.herbert@ColostomyUK.org

FREEPHONE HELPLINE: 0800 328 4257

Collaboration with TARGET OVARIAN CANCER

We were thrilled to be asked by **TARGET OVARIAN CANCER** to work with them on a new booklet about ovarian cancer and stomas. As you may know, when ovarian cancer is more advanced it can sometimes spread to the surface of the bowel. In some cases this makes stoma surgery necessary. We are just waiting to see the final copy of the booklet. It will be available via our website in due course. ■



Reversal – not always the answer

Sandra Willoughby

With surgical and medical advances meaning that stoma surgery is increasingly seen as a temporary measure, the subject of reversal surgery is set to remain topical for the foreseeable future.

Readers will probably recall that we looked at the matter in some detail back in the Autumn 2018 edition of *Tidings*. Jennie Burch, Head of Gastrointestinal Nurse Education at St Marks Hospital gave the lowdown from a healthcare professionals point of view, and pointed out that the decision to proceed needed to be set against likely bowel function afterwards. My interview with Xenia Standbridge fleshed out the picture further, with some insights from a person who had recently undergone the surgery. As we found out, while Xenia's outcome was ultimately positive, her post-op recovery came with its fair share of ups and downs. But what happens when there are more downs than ups and the result isn't as expected? This is what happened to Sandra Willoughby who I spoke to recently.

The start of Sandra's story will have a familiar ring for many ostomates. Towards the end of 2012 she started to notice blood when emptying her bowel. Her GP at the time diagnosed this as piles. The problem continued intermittently for the next 18 months, but came to a head one weekend when Sandra passed so much blood her daughter thought she should go straight to hospital. Sandra, however, resisted, as she didn't feel that she was an emergency. Aware of the pressure A&E departments are under, she was determined to go through 'the proper channels'; a view many of us will understand and sympathise with. Hence early the next week she booked an appointment at her local surgery, where she was seen by a young 'no nonsense woman doctor'. This led to an urgent hospital referral. Although at this point, many people would have feared the worse, Sandra's

overriding emotion at the time was relief. Relief that something was finally being done to establish the cause of her problem and (hopefully) treat it.

The consultant did an internal examination and confirmed that he could feel a mass. Sandra then had blood tests and a colonoscopy, after which a diagnosis of stage three bowel cancer was confirmed. The only saving grace was that the consultant said: "we can deal with it". These words helped Sandra, a naturally positive person, to remain upbeat throughout the treatment that followed. This included radiotherapy pre-op and then chemotherapy after a laparoscopic lower anterior resection and temporary ileostomy was formed in February 2014. However, as you will see, Sandra's positive outlook was soon to be sorely tested...

In February 2015 Sandra saw her consultant again where it was agreed to proceed with a reversal. Sandra left this meeting under the impression that normal bowel function would be restored. Sadly, the opposite occurred and post-op Sandra found she was unable to empty her bowel properly. The feeling that she needed to 'go' was with her constantly. In the nine months that followed Sandra became incontinent and her skin became very sore. The impact on her life was far-reaching. She lost two stone in weight and had to move into the second bedroom as she didn't want to keep her husband awake all night. Sandra tried everything, from visiting her GP, to altering her diet, to contacting various bowel charities, but nothing seemed to work. In the end Sandra reached the point where she was so desperate, she was prepared to try anything.

Luckily, before the reversal, Sandra had started to attend a stoma support group run by her stoma care nurse (SCN). And it was this that proved to be her salvation. Although the post reversal problems had

placed considerable restrictions on Sandra's ability (and confidence) to travel far from home, she still managed to attend the support group and the open day it periodically holds at St James Hospital, Leeds. It was here that she saw a demonstration of the Coloplast peristeen pump for anal irrigation. Sandra immediately spoke to her SCN as she thought it would be worth having a go with the system. Her SCN agreed and took matter forward, as a prescription for the pump is required. Shortly afterwards Sandra was visited at home by a registered nurse from Peristeen, Charter Healthcare who demonstrated the pump to Sandra and taught her how to use it. Sandra remembers this visit very well, as it took her so long to irrigate on her own, the nurse had to leave for another appointment and then come back again! Since then Sandra has never looked back. Irrigation has, quite literally, solved her post-reversal problems. She is now fully in control, fully continent and needs to irrigate just once every 48 hours. Amongst other things this has meant she can travel abroad again, confident in the knowledge that no accidents will occur. As Sandra said, the pump even comes in a carry case that is ideal for travelling.

At **Colostomy UK**, we wouldn't want Sandra's story to put people off going ahead with a reversal. But, what it does do is to reinforce everything Jennie Burch at St Marks Hospital said in the Autumn 2018 edition about considering likely bowel function afterwards. If you have had a reversal and are experiencing problems, then you shouldn't hesitate to contact your medical team. If you would like to speak to someone that has had a reversal, then call our Stoma Helpline: **0800 328 4257** or e-mail us: **info@ColostomyUK.org** and we will be happy to arrange this. ■

Written by
Richard Biddle

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Parallel Lives

Tracy Ross and Lucy Gough

This is a story about a series of bizarre coincidences and the kind of support that only one ostomate can give to another. It's about sharing problems and the blossoming of a close friendship. More than anything else, it's about two women who happened to join our closed Facebook support group...

Let's start with our two ladies, Tracy and Lucy.

Tracy's story

Originally from South Wales, Tracy now lives on the west coast of Scotland in a small town near Loch Lomond. Before her stoma surgery, she was a police firearms officer. Ongoing health issues have meant that Tracy can't do such active work anymore and so she has exchanged her holster for a position in the police control room. Tracy has been with the force for 20 years now and, if that isn't enough, is married to a policeman too! She has two children, Arwen (14) and Chloe (12). A border collie completes the family.

Tracy's problems started after the birth of Arwen. In the four or so years that followed, she suffered multiple prolapses of her womb, bladder and bowel. Tracy had an hysterectomy, but shortly afterwards suffered paralytic ileus* and her bowel stopped working. As a consequence she had a loop colostomy in March 2015. She was 39 years old. This was made into an end colostomy in 2016 following a hernia repair. Tracy then had a further hernia repair and her stoma refashioned in May 2018. When I spoke to Tracy in the lead up to Christmas, everything was ok as far as her stoma was concerned, but unfortunately she was having problems with bladder function.

Tracy still remembers the six weeks after her first bout of stoma surgery; it was a dark time for her. Having previously been so active she quickly became frustrated. Being

stuck indoors also gave her too much time to dwell on what had happened and worry about what the future might hold. Stuck in this vicious circle, she became desperate and almost suicidal. Tracy's family supported her as best they could. The Police Firearms Officers Association did the same. They sent her presents and also put her in telephone contact with an officer in the Met who had had a stoma and reversal. Tracy spoke to him at length. Tracy said all this helped, but what she lacked most was regular contact with someone (e.g. an ostomate) who understood what she was going through. In the absence of this simple understanding, Tracy started to think that she was the only person of her age facing the prospect of life with a stoma. Two months post-op and while searching the word 'support' on the internet, Tracy happened across our closed Facebook support group and joined immediately.

Lucy's story

Lucy was born in 1969 and lives in Sutton, Surrey, where she works for the London Ambulance Service in their control room. She has been with the service for almost 13 years.

Lucy started to have bowel-related problems in 2011. She saw a couple of doctors, both of whom concluded that these stemmed from haemorrhoids. As the problems persisted, Lucy went back to her GP Surgery, who referred her to A&E at East Surrey Hospital. It was here that a perianal abscess was diagnosed and Lucy was told to return in a few days so that it could be excised and drained. Days after the

procedure was carried out, Lucy developed a fistula and her doctor referred her back to hospital. Matters quickly escalated from this point. Two weeks later, after tests and biopsies, Lucy was diagnosed with anal cancer. In June 2011, at age 41, Lucy had an ileostomy, followed by five and half weeks of chemotherapy and radiotherapy at the Royal Marsden in Sutton.

This didn't mark the end of her problems. Although Lucy thankfully got the all clear after five years in remission, like many ostomates she developed a parastomal hernia, which required a surgical repair in December 2014. Tests at this time on muscle condition also determined that a reversal was not viable and her stoma would be permanent. In the year that followed, Lucy developed another hernia which, again, required surgery (December 2015). Up until this point Lucy had been pretty much coping on her own, with the help of her stoma care nurse. It was while recovering from her second hernia op, where she was off work for six weeks, that Lucy 'stumbled' across **Colostomy UK** and the closed group. It all came about because she decided to search for 'colostomy' while on Facebook. She joined shortly afterwards.

Meeting over the ether...

The ladies joined the Facebook group within six months of each other and both found it a game-changer. Tracy described it as a "revelation", Lucy "another world". They were immediately struck by the friendliness.



Both started as passive members, rather than actively contributing themselves. Building confidence in this way is perfectly understandable. It was also during this 'phase' that the ladies discovered they were far from alone; there were plenty of other people out there with the same conditions and challenges. It also became clear to them that people of all ages had stomas, rather than it being just an 'old person's' thing, as is so often wrongly assumed. Tracy and Lucy commented that just reading other people's posts provided them with emotional support. Tracy also shared many of the posts with her husband and oldest daughter. This struck me as important. I'm sure many readers will agree that it is sometimes difficult to find the right words to express what you are feeling or going through. This is perhaps especially the case for an ostomate talking to a non-ostomate. In effect, the posts were Tracy's 'prop', enabling her to communicate in new and positive ways with her family. Both ladies found the regularity with which posts appeared on their Facebook feed and the often mundane nature of these posts helpful too. People sharing funny anecdotes or pictures of their pets was a constant reminder to them that 'normality' was achievable and, perhaps, just around the corner.

As members of the Facebook group will know, it is also a good place to share stoma issues and get practical advice. It was just such an issue that prompted Tracy to break her duck and make her first post. This ultimately led to her meeting Lucy over the ether. While doing the school run one day,

Tracy started to suffer pain around the area of her stoma. She thought she would see if others in the group had experienced the same and what they had done about it. Lucy was one of the first to reply and said that it could be a hernia (as it turned out to be). By this point Lucy had already had two hernias and so recognised the symptoms. Tracy acknowledged Lucy's comment, but didn't think much more about it, until a few days later, when she received a message from Lucy asking how she had got on at the hospital. This simple act of compassion and human kindness marked the start of their friendship. As both ladies told me, the connection between them was instant. They began exchanging private messages, before moving to e-mails and then to talking on the phone. Lucy explained that, although by the time of their first contact she was something of a stoma expert (having had her surgery five years earlier), the relationship was a two-way street right from the off – with both women helping and supporting one another.

As far as Lucy is concerned, Tracy was (and is!) a breath of fresh air and gave her a new lease of life at a time when she was feeling lonely and detached. Since their initial meeting, their friendship has gone from strength-to-strength, even though they have never met one another in the flesh. As well as being there for one another for all the challenges that life with a stoma can present, they also share news and do all the other things that you would expect between close friends. As their friendship has deepened, so the coincidences I

mentioned at the start have started to emerge. Aside from both having stomas and both having had hernia repairs, they share the same birth month and do similar jobs. Both work in the control rooms for the emergency services. And, as they have discovered, despite working for different emergency services, they use the same command and support systems and even have the same type of radio! Thanks to Tracy, both also now wear the stoma bag covers which she had specially designed. Lucy's proudly displays the London Ambulance Service emblem and Tracy's the Police emblem. The two laugh that these should form part of the uniform for ostomates in their respective service!

I hope that you've enjoyed hearing about Tracy and Lucy. If you are already a member of the Facebook group, then my guess is that you will have nodded in agreement at least a few times while reading their story. If you aren't a member, then it's easy to join. And, remember, there is no pressure to be 'active'. It's fine just to read posts and draw support from what people say and gather information from and comfort from hearing about their experiences. Who knows, maybe your next best friend is just a click away! ■

Written by
Richard Biddle

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PART
ONE

Trevor Alexander

My first encounter with Bowel Cancer came shortly after my 60th birthday when a large envelope dropped through my door. I had never considered myself a candidate for cancer as fortunately none of my family had ever experienced it and I had lived a trouble-free life as far as my health was concerned. I was lucky enough to retire a few years before and was fully adjusted to a life of leisure.

Poo on a stick, a new experience from the NHS but if they have sent it to me better to do it and get it over with! The results came back as I expected, and I carried on with life and repeated the test two years later with the same result. I have to admit at this point I was a little overweight and, as a result of my working life which involved a lot of lunches, had developed a great taste for red wine over the years. When the next test came, I was 66 and although having the usual little aches and pains that accompany that time of life felt fine so sent the test away and awaited the result as usual.

A week or so later I was sent another test and asked to repeat it and a week after that I was offered a consultation to 'explore some possibilities'. After several tests which I'm sure we all go through and a MRI scan, I was invited for a consultation at Hexham General Hospital. I suppose I was a little naïve as I told Jill, my wife, to go and have

a cup of coffee while I saw the consultant and I would be back quite soon. I only realised something wasn't right when the nurse suggested that maybe my wife should come in with me. We were introduced to Mr Slater who I have got to know very well since!

I am pleased that my professional life didn't involve telling people they have cancer. Although being involved in the life assurance business for many years I have unfortunately seen the results of cancer both in terms of changing lives and finances. In the next 15 minutes we were told very professionally that I had bowel cancer and had certain options. Mr Slater explained that because of where the cancer was, I would need a fairly lengthy operation, there was a chance I may die, and...he had a slot in ten days' time! I looked at my wife and it was obvious that there was actually no option so we may as well get on with it. Fortunately, we are a positive couple. My thought at the time was that here I was in late June and would I be fit enough to go on a cruise I had booked in September and be able to go to Florida in November? The car was very quiet on the way home.

I openly admit I was terrified on the way to hospital but the staff were all very supportive and having sorted out our finances etc. in

case of a bad result, I'm pleased to say that I woke up some hours later a little groggy but still in this world! The next few days were awkward to say the least as unfortunately my coccyx bone had been removed as part of the operation so not only did I have all these tubes and bags attached I also had great difficulty sitting down.

Even though you think you know what to expect I found it quite surreal at times. I thought maybe this isn't really happening? Maybe I will wake up and everything will be back to normal again? Of course, this never happened. I had this strange stoma thing and there were new skills I had to learn quickly, like how to change colostomy bags and small things like walking again...even having a shower seemed to be a major project and the thought of eating was tempered by the thought of what would happen when it eventually came out again. I remember swearing a lot the first few days when I seemed to need three hands to do things but, with the help and terrific encouragement of all the nurses at Cramlington Hospital, all the initial hurdles were overcome. 10 days later I emerged into the July sunshine and very gingerly got into the car and went home. Barry Slater had told me not to do anything stupid when I eventually escaped, explaining that

CONTINUED ON PAGE 17, COLUMN 1

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CONTINUED FROM PAGE 15 COLUMN 3

everything has to heal, and it will take time. Maybe I won't get on my cruise in five weeks I thought, but I was still determined to go to Florida in November.

Once home I realised quickly that a sense of humour was going to be very important. I still couldn't sit down properly and spent the first couple of days, much to Jill's amusement, trying to find a combination of seat and cushion which I could sit on for more than five minutes. I spent most of the day leaning against the back of the settee and sitting on my office seat with a wonderful cushion with a hole in the middle borrowed from one of my neighbours. I ate very little in hospital which did wonders for my weight but not much else. However once home I started eating again and had to deal with the consequences! On the brighter side I had a string of district nurses who turned up each day to change dressings. Nurses seem very young these days and I soon got used to them chatting away about their nights out or holidays whilst I was lying naked face down on the bed being inspected and having large sticking plasters applied!

Gradually over the next couple of weeks things improved and the day arrived that I decided life had to start again and a trip to the pub was called for. I suspect that I was

no different from anyone else in that my digestive system and stoma were not really in sync with each other yet and I never really knew when things may start to move. I had got to the point when movements generally occurred mid evening so I guessed I would be OK and equipped with my emergency pack I went for a pint. This is when I learned that alcohol can have an interesting effect and after two pints I was heading for the toilet pretty quickly!

By the end of August (approximately six weeks in) I was getting the hang of changing bags away from home but still far from confident about going to restaurants. Whenever I started eating I would be worried and this in turn seemed to start a chain reaction and my friends got quite used to me suddenly disappearing for 10–15 minutes while I sorted myself out. Although the cruise was cancelled in September, I started playing golf again (with care) after six weeks or so and my various scars etc. had healed enough to be given permission to go to Florida at the beginning of November – so the first target was met.

A nine-hour air flight proved entertaining but I had spoken to the cabin crew just in case and they did a magnificent job of getting me to the front of the toilet queue when required. I think they were perhaps more worried about the potential

consequences than I was! Christmas came and went without drama, but I was having problems with pancaking. The pouch would come off and, depending on where I was at the time, cause panic. This happened in the middle of a dentist appointment, when I had to leave rather rapidly half way through having a filling done! Fortunately, I discovered quite early on that if you are upfront and open (especially with friends) then most situations, although maybe a little embarrassing, are just dismissed as one of those things.

The other thing I learned quickly was to talk over any problems with my stoma nurse, who was always helpful and would suggest things to try. I went through my first six months a little apprehensive but with the support of Jill, friends and all the support from the care staff made a full recovery. I still had problems with irregular movements and pancaking which proved irritating. Although these aren't life threatening they certainly had a negative effect on me. I was certainly not a happy bunny walking around with a part filled bag and didn't want to be doing this for the rest of my life. It was then, by chance, that a friend gave me a copy of *Tidings* and I discovered... ■

You can find out what Trevor discovered in part two, which will be published in the next edition.

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

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Weight gain following stoma formation

**Sophie Medlin
Dietitian**



It is very common for people to gain weight following stoma formation. There are many reasons for this such as:

- ◆ Increased absorption of nutrients and better food tolerance (mainly Ulcerative colitis patients)
- ◆ Reduced intake of low calorie foods like fruit and vegetables to control stoma function
- ◆ Reliance on starchy, 'stodgy' food to bind stoma output
- ◆ Changes in body image
- ◆ Alterations to relationship with food

Unfortunately, gaining significant amounts of weight following stoma formation can increase the risk of complications such as hernias and of course, as with the rest of the population, an unbalanced diet leads to an increased risk of diabetes, heart disease and some cancers. This can lead to well-meaning healthcare professionals and perhaps friends and family drawing attention to these risks and encouraging weight loss.

Sometimes, a useful analogy is to compare having a stoma to being given a pet to look

after that you don't particularly want. The pet has to go everywhere with you, either permanently or temporarily. The better you care for the pet, the easier it is to look after and the happier you feel. The more you reject it and don't care for its needs, the harder it is to manage and the less friendly it becomes.

Looking after your stoma by taking care of your health is so important, but this can be very hard to do if you have struggled to accept your stoma. Unfortunately, weight loss is never easy and it is further complicated for many people with a stoma, by the need to regulate output through dietary changes that tend towards a less balanced diet. Everyone with a stoma has a different experience of eating, from the reason for stoma formation to the length of bowel remaining, other medical conditions and our individual food culture. There are very few foods that suit every ostomate. While many people with a stoma can eat everything and anything, lots of people find that there is a long list of foods that don't agree with them. This can lead to feelings of isolation and those ostomates can feel judged by those who can eat freely.

This means that designing healthy eating information for people with a stoma is really tricky! It also means that for many people, standard means of weight loss, for example, weight management groups, booklets from GPs and online information is inaccessible and can cause people to feel like they might as well not even try.

A different approach (applicable to all) is to consider the reasons why you're eating and focus less on what you're eating. The foods we choose and the reason we eat them is very often not "because it's healthy and I am hungry". The reason we're eating is often because we're bored, unhappy or stressed. Eating works temporarily under these circumstances because it lights up the reward centre in our brain, making us feel good. Unfortunately, if you are trying to manage your weight, especially if you are trying to manage your weight because the doctor told you have to, you will often experience guilt associated with eating the 'wrong' foods which can lead us to feel like a failure and, often, to eating more.


The way to manage this is not to download a more restrictive diet or buy a new diet

CONTINUED ON PAGE 21, COLUMN 1



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CONTINUED FROM PAGE 19 COLUMN 3

book or to ask your next-door neighbour how he lost weight and copy him. The best way to understand your eating behaviour is to understand why you're eating. Try keeping a journal of what you eat and write beneath each entry "I ate this because..."

This is not an exercise in self-judgement but a way of understanding your eating behaviour better. If you're regularly writing: 'I ate this because I was bored', you might want to try and find a hobby or a creative outlet that gives you that stimulation you're looking for from food. Try colouring or doing crosswords while you're watching the TV, it might help to distract your mind and boost your happy hormones.

If you're writing: 'I ate this because I am unhappy', it is time to address the reasons for the underlying unhappiness. It might be that you need to get some professional help and your GP would be a great place to start with this. It might be that you know the causes of your unhappiness and you can begin to address them, either way, the over-eating is as symptom of your distress, not the cause. It is the underlying issues that need to be tackled.

If you find you are often writing: 'I ate this because I was stressed', it's time to find new stress management strategies! There are some great ideas online including

controlled breathing and meditation. Obviously in an ideal world you will also reduce the causes of stress in your life but of course, that isn't always possible.

If you often find that you're eating something because you're on the run and you can't find anything healthy to eat, it would be a good idea to try and plan ahead a bit for your day and maybe stock up on healthy food and snacks you can keep with you.

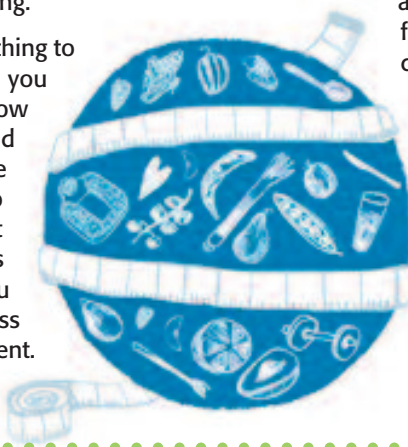
Gentle exercise, even just stretching can light up the same reward centre in your brain as food does. Chatting with a friend on the phone or watching funny videos will also help. Creativity and hobbies do the same thing. There are plenty of healthy behaviours that we can do that can displace some of the overeating.

The most important thing to remember is that you already know everything you need to about how to lose weight. There are no secrets. The diet industry will always be waiting to sell you a new weight loss method or supplement. We buy into a new diet hoping that we

didn't know what we should have been eating before when really the solution is in understanding why we are eating.

Once you have understood and developed some strategies to overcome the reasons for over eating, think about the basics. Try to have plenty of fruit and vegetables and lean protein. If you find that vegetables affect your output, try choosing vegetables from the lower fibre list. Snack on fruit when you can or try peanut butter on oat or rice cakes. Rice cakes can be a great way to thicken output without giving a lot of extra calories.

Remember that weight gain is always a symptom of a problem and not the cause of our problems. Healthcare is currently set up in a way that treats weight gain as THE problem without finding real solutions to the causes for weight gain. ■



Sophie
DIETITIAN

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

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- Payment – cheque or credit card*

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(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)

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Signature of self or carer: _____



Please **tick** as appropriate:

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

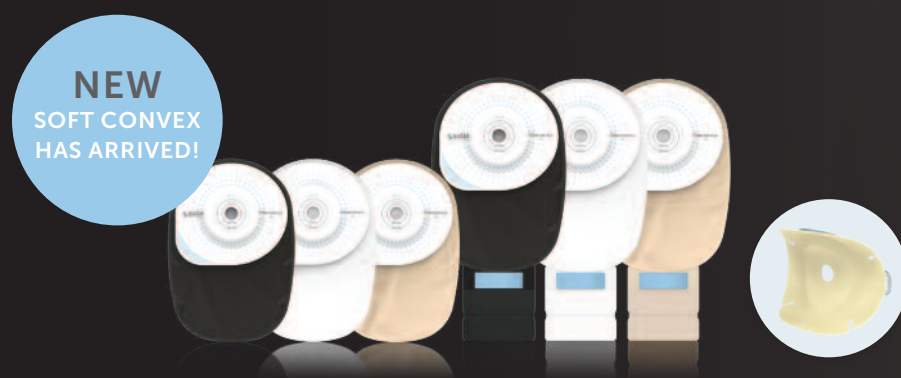
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BETTER NOW"

Your letters and e-mails

Ed's note: We have a good selection in this issue. Dave Funnell got in touch to say what an impact the last front cover had on him. R H has some good advice for anyone flying long haul. Our other letters all tap into topical issues. We have a couple that engage with plastics and stoma bags and another which raises concerns about the new NHS formularies.

Dear Editor

I just want to say a big thank you to the young lady on the front cover of Spring 2019 *Tidings*.

I took one look at the cover and everything hit home. All the words printed on her body were the same things that been in my head for 26 years. It's been hard to explain all the things I have gone through until I saw that cover. I know to a lot of people they're only words, but to me they sum up what it's like having and living with colitis and Crohn's disease – from the pain we go through to the stress we have to put up with not knowing what's coming next in our life.

I was diagnosed with colitis at the age of thirty and lost my large bowel. In some ways I was lucky as for a few years I had a J-pouch made in my stomach and lived quite a normal life after the operations and complications I went through for three years. But 18 years later when problems started again with pains and fistulas I ended up having an ileostomy at fifty-one, hoping that all the pains will stop and I could start leading a normal life.

I'm now 56. I have been diagnosed with Crohn's and been put on injections to help my situation. Things are not much better but you have to start living with this. One thing that sticks in my mind is people don't realize what pain we go through with these diseases and how it never seems to stop. Good days are few and far between. I started this email because of your front cover and it hit me so hard in a good way to know it's not just me feeling the same way. I would like you to thank Jessica Logan from me for making me realise there are other people out there suffering the same as me.

**Many thanks
Dave Funnell**

Dear Editor

I have recently become an Ostomate and I decided that a holiday would help me regain some of my confidence in travelling with a stoma.

I requested and received the very good travel advice from **Colostomy UK** and so went ahead and booked a summer break in Orlando. This meant a long haul flight and a little more thought was needed to ensure that my travel plans went smoothly.

I read all the advice and made my plans accordingly.

As advised, I paid a last minute visit to the toilet, renewing my pouch before getting on the plane to make sure that my pouch was clean and empty as I boarded. I had contacted the airline and requested a seat by the toilet – so another worry sorted out, I thought!

I had forgotten that I would be the one person on the plane who would not need to rush to the loo – as my pouch would hold any movement from my bowel until I was comfortably ensconced in the on-board toilet.

What I had not given a thought to was during the journey I would be constantly disturbed by other passengers wanting to use the toilet. At night – it was the opening of the door – the light shining through – the closing of the door and then the light again – and another closing of the door. During the day I was entertained by the gossip and conversations taking place by passengers queueing up to use the toilet. So, a piece of advice – request a seat some rows away from the actual siting of the "little room".

Apart from that, my holiday was a wonderful success. Following the travel advice booklet and having the travel certificate on me as I

went through security at both airports here and in the States, I was confident the whole time of the holiday.

I am looking forward to booking another long haul flight to an exotic destination this time sitting in the middle of the plane!

RH

Dear Tidings

I wonder if you could reassure me about my problem of ordering my stoma supplies.

I have had my stoma for many years with no problems when reordering my pouches and accessories. I have always made the telephone call to the supplier – regardless of the manufacturer of the pouches and have placed my request with the order clerk. This is then called across to my surgery and a prescription is requested to cover the order. Once received – this prescription is actually the "cheque" for payment from surgery to supplier.

If I have been recommended by the stoma care nurse to try a different pouch or try other products I notify my surgery and keep them up to date with the changes I might need made to my prescription. Until recently I have never experienced a problem. Now, however, I am receiving less boxes of pouches than I have requested. On asking why (to the supplier) I am informed that my surgery has limited my prescription and adjusted my request.

I have heard a lot about ostomates "over-ordering". I understand that this costs a lot of money when ostomates store items and then don't use them. I am not one of those!

I found it difficult to understand how my request could be altered without asking me to explain why I needed the amounts I requested on my prescription.

I made an appointment with my GP – to find that he had no knowledge of what exactly a stoma was and how it worked. I explained how a stoma works in removing the waste material from my body and why it was important and necessary to have the pouches etc on my prescription.

I was told that my stoma care nurse would sort out my stoma supplies – and the surgery would be guided by her. I immediately tried to contact her and explain what was happening. She said that due to the new formularies introduced by the NHS, restrictions were in place to stop certain products being placed on prescription. There was even talk about limiting adhesive remover sprays to patients.

I use adhesive remover sprays, and barrier wipes. These were thought, by the NHS, to be unnecessary. Despite my skin being torn by removing the pouch without the aid of the spray and soothed by the barrier wipe this was suggested as over-ordering.

I came away feeling bruised and battered and completely at a loss as to where to go next to solve this problem. The answer was to write a detailed letter to my GP. I stated that unless I was able to obtain these items then I would have to attend a wound dressing clinic to ensure my skin and stoma were treated to allow me to continue my life with a stoma without the terrible consequences that stopping just these two items would have on my life.

Since then I have spoken to many ostomates who are also experiencing similar problems. Suddenly the quality of life that we were experiencing while living with a stoma has been disturbed and sometimes taken away without any thought or concern for anyone's well being.

I read all the articles in *Tidings* and I would like to think that an article written by a GP or Stoma Care Nurse, explaining the decisions of the CCG on stopping stoma items could be printed. Replies from other ostomates could be added to show how they have managed while facing this situation.

I have recently read an excellent blog from an ostomate – Nathan Wheeler – echoing most if not all my concerns. Perhaps he could write for *Tidings* and let us read how he coped with the problems I have listed.

Jane R

Dear Editor

Disposal of a used pouch is now becoming an issue about "plastics".

There are flushable pouches that are available but the majority of ostomates use pouches that need to be disposed of and replaced on the stoma by a fresh pouch.

This has always been quite easy – empty the contents into the toilet and then wrap the dirty pouch in a plastic disposal bag (nappy bag/poo bag/bag supplied by your stoma items supplier) and placed in the household waste bag or bin.

Now – if we are to take note of the advice around the disposal of plastic we should be concerned about what happens to our plastic disposal bags.

I cannot think of an alternative and, so, as long as we dispose of our stoma items in a responsible way I feel we are caring for the environment as best we can.

I know the manufacturers are researching the reduction of the plastic in our stoma bags but I cannot imagine a pouch that would not require a plastic liner so that we can be confident that the contents will not be leaking out and messing up our clothes. Gosh, how awful just to think about it.

I have just watched a video of a large machine that is recycling used nappies – and the idea might be to add our stoma bags to that disposal method. However, that must be in the future – depending on various Councils plans for the disposal of all household waste.

In the meantime do explain to those who wish to criticise us for using plastic – that sometimes NEEDS MUST. Maybe a letter to your Council asking when they will find a clean way to dispose of the nappies and our pouches might draw attention to this new method?

My advice is...not to feel guilty about the use of plastic but be aware of what you can do to help the green lobby.

FSA

Dear Editor

I have had a colostomy for 31 years and realised in that time I will have added at least 45,000 plastic items to waste. I am deeply grateful that I have been prescribed the bags I have used. These have enabled me to live an active and fulfilling life. I also know that having a permanent colostomy saved my life.

However, as we all know from David Attenborough's programmes about the impact of plastic on wildlife, particularly those in the seas of our planet, plastic is causing very serious environmental problems. And some of the plastic we all use will inevitably have ended up in the world's oceans.

According to the non-profit organisation Ocean Crusaders* over 100,000 marine creatures a year die from plastic entanglement (these are the ones found) and approximately 1 million sea birds also die from plastic.

I'm sure most of us reliant on colostomy products do not want to contribute to this death toll. So I urge **Colostomy UK** to work with your many business partners to help us all to reduce plastic waste and to find less damaging materials for the vital products we rely on.

Yours sincerely
Helen Kendall

*www.oceancrusaders.org

Please note:

Before acting on suggestions from other ostomates regarding medication or treatment you must check with your doctor or stoma care nurse that this course of action is suitable for you.



We look forward to hearing from you, our readers:

Send an e-mail to: **info@ColostomyUK**

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.

In a league



"Max is a fab role model and inspiration for young and old with and without a stoma"

Theresa

"I really needed today, to get my head right, not just because of my stoma. I needed to prove something to myself"

Michael

The lifestyle survey we ran in *Tidings* a few years ago told us that many people were fearful of physical activity after their stoma surgery. Amongst other things, they were unsure what exercise was safe. These findings, coupled with evidence that exercise aided post-op recovery and helped prevent parastomal hernias, led to the launch of our Active Ostomates project in 2016. Thanks to an initial grant from Sport England we were able to produce our *Sport and fitness after stoma surgery* booklet and pilot chair yoga at a number of support groups. As 2017 drew to a close, we were better able to appreciate the project's benefits to ostomates. Our booklet won 'Highly Commended' at the British Medical Association Patient Information Awards. The overwhelmingly positive feedback from the chair yoga sessions also made clear that being active was good for mental wellbeing too.

Early in 2018, Giovanni (our Fundraising and Development Manager) floated the idea of having a Team Colostomy UK Rugby League team. He hoped that being able to showcase ostomates playing a tough

contact sport would give those worried about exercise the confidence to get active again. The 'active' he had in mind wasn't just about playing sports, but included everything from gardening and walking to the shops to just going out. In other words, it was as much about mental wellbeing as it was physical health. As our plans developed, we also saw the potential for generating interest with mainstream media and using the team as a vehicle for raising public awareness about stomas more generally and highlighting the challenges that living with one can present.

Looking back, I know I speak for everyone at **Colostomy UK** when I say that the success of the team in achieving the above aims has exceeded our wildest dreams. Since then, our Active Ostomates project has not only appeared in the Rugby press, but has also been featured in *The Guardian online* and *BBC news online*. We have also attracted many high profile sportspeople who have willingly supported our work and shared what we are doing across social media. Thanks to sponsorship from SecuriCare, Pelican Healthcare, Cheney

Payroll Services, Welland Medical and Dave Kaye Associates, the team launched their second season with a match in April against Medway Dragons. The team we fielded had a couple of important additions. First there was seven-year old Max, our team mascot, who had his stoma formed as a toddler. Remarkably, he went on to score three tries and was unanimously voted as man of the match. Secondly, there was Ian Daniels who, for those readers that didn't know, is a consultant colorectal and general surgeon and also our president.

So what did the match mean to those who played and those who watched? Has 'Active Ostomates' really helped get ostomates active and raise general awareness? I caught up with Ian Daniels after the game and asked him to jot down his thoughts:

*Saturday 20 April, and one apprehensive **Colostomy UK** President managed to get his boots on to play for Team Colostomy UK. If I was worried (over-50 and not having played rugby (of any sort for 20 years) I need not have been...what a team of different*

of our own

WELLBEING



"An absolute pleasure to be part of a great day, well done Colostomy UK for making it happen"

Mark



"They let a little hero who is seven years old with his own stoma take part. It's important to show little boys like Max that anything is possible regardless of your circumstances"

Iffy

sizes, sexes and stories all with a passion for the camaraderie of the game and no fear...especially from Team Mascot Max, an amazing young man. In the presence of rugby league royal family (Tom Kaye) and his warm-up routine and wearing proudly the Purple shirt we were ready...to play a bunch of teenagers and a couple of old men!

Although the rugby was fast and furious, it made me realise that while we think we are different – well we were not. We are a bunch of people, those fat, old and slow (yours truly), those small, fast and whippet-like with the ball, those who run like

a bull in a china shop and those that require a shout of "get four on him to stop him!" but all enjoy sport (of any standard) and being team mates, enjoying the group, trying our best and giving those watching a laugh...and some pride in seeing everyone play and be a part of the team.

So why does this matter? Well it does...whether you are an overweight consultant surgeon, or playing for the family member with a stoma, or playing after surgery that leaves you with a stoma, or playing with a pouch, or playing having had bowel restored, the key point here is playing...getting out and doing something that makes us feel good, that we get enjoyment from, that allows us to play with whatever restriction we

have, and gets us fit...and that's the key...it's about improving our health, our tone, and shape, but also being aware of the sizes and shapes that make us all different... Go Team Colostomy UK!

Hopefully Ian has started to answer some of the questions I posed earlier. But if you need any further convincing then please take a look at the quotes surrounding this article. They were made by ostomates and their friends and families that attended the day. Some played on the field, some supported but, importantly, they were all active and a part of something bigger – Team Colostomy UK.

If you would like to find out more about getting active, either on your own or through your support group then please get in touch with Giovanni at: Giovanni.Cinque@ColostomyUK.org

Visit our website to keep up-to-date with our Active Ostomates project and get all the team news. ■

Written by
Richard Biddle

"They're making leaps and bounds to get rid of the stoma stigma... their match against Medway Dragons was proof of that"

Iffy



Looking for online support?

The Colostomy UK closed Facebook group is a safe and friendly space where you can speak with thousands of other people who live with a stoma. This welcoming community is a place to share hints and tips, stories and news and to reach out for support from other people with a stoma.

Search for **Colostomy UK support group** on Facebook and request to join.

We look forward to welcoming you.

www.ColostomyUK.org

Stoma helpline:

0800 328 4257





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See our main advert on page 52.

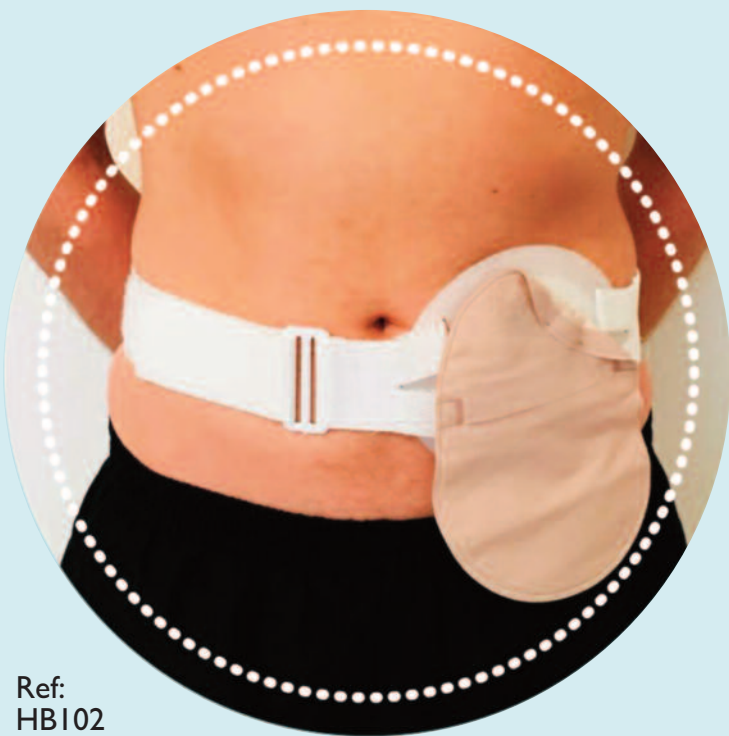


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Ref:
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Do you irrigate? If not, are you interested in trying? If you feel you would like to try irrigation you should first contact your stoma nurse to see if you are a suitable candidate. If you get the go ahead they will then arrange a time to teach you. For more information see the **Colostomy UK** website or obtain the Irrigation and you DVD using the form on page 17.

Irrigat



Sarah Squire
Volunteer
E: info@ColostomyUK.org

If you have any questions, comments or experiences of irrigation you can email info@ColostomyUK.org or write to me at **Colostomy UK**.

Tidings readers will remember Anthony from a previous edition when he was new to irrigating. Here, he updates us on how he's doing further down the line.

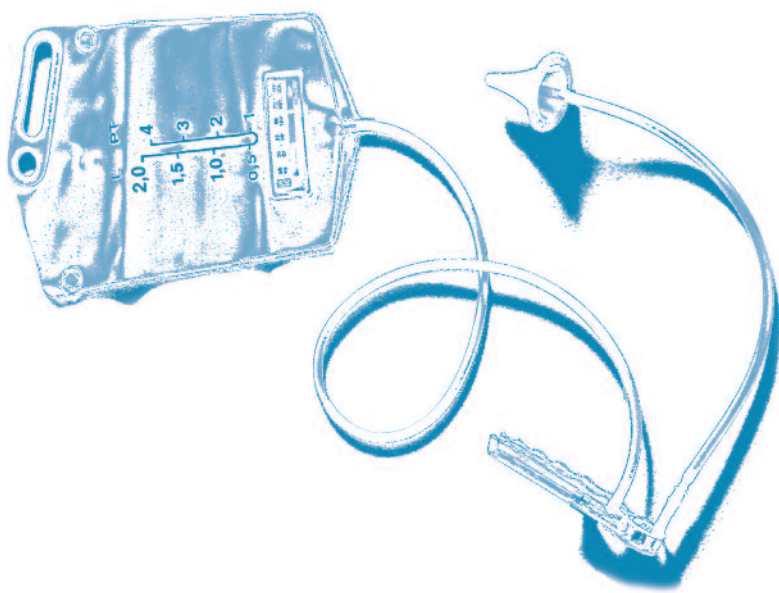
I appeared in the Summer 2016 edition of *Tidings* when I was six months post-operation and had just started using irrigation to manage my permanent stoma. Two years on, I thought readers would be interested to hear how I am getting on. I'm now a big advocate of irrigation.

I allow up to two hours from start to finish for my irrigation; it is very rare that I have to go beyond this amount of time. Once the initial output is done I clean the sleeve, flushing it with fresh water, peg it up and I'm free to do what I want around the house. I go back to the loo two or three times to empty out my makeshift bag, flushing the sleeve clean each time. I usually know when the output is finished but leave it for the two hours just to make certain. I started using a B. Braun IryPump in my first year of irrigation. It's a great piece of kit which I find far less fiddly than the hung water bag method. It's a matter of personal choice more than anything else.

It took me a few weeks to perfect my irrigation method with both the gravity bag and the IryPump: using different water temperatures, different water flow etc. I admit I have had a

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Freephone: 0800 389 3111
www.sashstomabelts.com



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couple of hiccups along the way, but most times now it's all pretty straightforward. I irrigate every 48 hours and only use caps in-between time. There has been the odd occasion when I have found some very small output in my cap, but this doesn't concern me as I know I can still last until my next irrigation is due.

I haven't looked back since I started to irrigate in 2016. I have been active all my life and continue to be so. Walking, jogging and swimming long distances is not a problem for me. I have also travelled the world in the last couple of years with no problems at all, just a little organisation around where and when to irrigate. Most countries have good clean tap water that can be used. However in some places you need to use bottled water, so I take a small kettle with me to warm the water. I also take my IryPump and make sure it is fully charged. I take a back-up water bag system with me too, just in case, although touch wood I have never needed to use it.

The equipment required to see me through a long stay abroad can equate to quite a big bag full. You have to remember to take everything you need plus more in case you are held up anywhere. I use a large rucksack which stays on my back while travelling. I have found airlines are generally good and allow an extra carry-on bag for medical equipment, (I don't let this out of my sight when travelling!) but it is worth checking with them well in advance. Although stoma caps are fine in the UK, I have found with really hot places, the climate along with lots of swimming, means I have to add flange extenders to keep the caps in place. This isn't really a problem, but it's worth bearing in mind. I just have to remember to take enough with me to cover the time away!

The only down side to my story is I have developed a parastomal hernia, which I am not too happy with. My stoma care nurse has told me that it won't be repaired unless it becomes life threatening. I guess this is understandable when you consider the

pressure the NHS is under, believe me I couldn't be more grateful for the NHS over the last few years. I have looked into getting the hernia dealt with privately and it runs into the tens of thousands of pounds so it looks like I will have to put up with it for now. It's not affecting my irrigation at all, it just looks a little unsightly. Having been reasonably slim most of my life I think makes it harder for me to deal with. That's life with a stoma!

I recently had my telephone consultation for my 3rd year cancer blood test results and I'm happy to say I'm still cancer free three years on! ■

Please remember these experiences are personal to Anthony. Before acting on suggestions from other ostomates you are advised to check with your stoma care nurse.

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<input type="checkbox"/> If you do not wish your name to be publicised if you win, please tick here	

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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
(please tick payment frequency and write amount in box)	<input type="checkbox"/> Every 13 wks £13	
	<input type="checkbox"/> Every 26 wks £26	
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Total Payable		=

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)
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To: The Manager: Bank/Building Society	
Address:	
Postcode:	
Name(s) of Account Holder(s)	
Branch Sort Code: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	
Bank/Building Society account number <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	
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: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	
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:

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Signature:	Date:
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Gut Feeling...

There's no denying the importance of support groups. The evidence is there for all to see. Search the internet and you are confronted with a dizzying array; just about every patient group and condition seems to be covered. Some groups meet in village halls, some meet in coffee shops, some even meet in people's front rooms. Increasingly, members never see each other in the flesh but 'meet' instead via their computers in a virtual world, just as Tracy and Lucy did through our closed Facebook support group (see page 10). Indeed, support groups are such a characteristic of the post-industrial landscape they even feature in fictional works. Chuck Palahniuk's transgressive novel *Fight Club* offers perhaps the most famous example. Tyler Durden, the book's troubled narrator, finds attending support groups (even those unrelated to his problem of insomnia) is the only way he can get to sleep at night. At this point, you're probably wondering where this article is going...in case you had started to worry, let me allay your fears. I'm not about to announce 'Ostomate Fight Club' as a new strand of **Colostomy UK's** Active Ostomates project! Instead, I wanted to tell you about a gap in the ostomate support group 'market' and how some enterprising stoma care nurses have managed to plug it in their part of the world.

We first got wind of what Michelle Hill and Fliss Nutting had been up to, when they presented their work at the Association of Stoma Care Nurses' annual conference last year. But, for them, the story started back in 2014 when Leicester Royal Infirmary (where they all work) took over the area's paediatric stoma care service. The needs of this patient group differ in many ways to adult stoma patients. As the ladies explained each age has its own set of challenges. With babies it's all about trying to get stoma bags to fit, which can be especially difficult if the baby is premature. Then when a baby starts to move, bag security is a problem. Feeding issues are another concern. As a child gets older, so fresh challenges emerge. Integration into nursery and school can be tricky, including making sure that the child is able to participate in the same activities as their peers. For adolescents concerns around body image and relationships understandably enter the mix. The parents of children with stomas need lots of support too.

Although the service offered by Leicester's paediatric stoma care team is comprehensive, the ladies quickly identified that peer-to-peer support (both child to child and parent to parent) was lacking locally. Feedback from parents and children

suggested this was needed and, with the benefits of support groups well documented, the ladies decided to set one up themselves. The first issues they faced were of a practical nature. Support groups need somewhere to meet but, given this was a group for children of all different ages, the venue had to be more than just accessible. It also needed catering facilities and had to be suitable for hosting a range of play activities, including arts and crafts. Once the venue had been secured the next thing was advertising the group's first meeting. As SecuriCare nurses, the ladies were able to do this through SecuriCare's Hand in Hand magazine. They also put posters up in all the relevant wards at the hospital. Even so, as Michelle explained when I spoke to her, it was an anxious time. They worried that no one would come, or that people wouldn't return. Although the first meeting was a success, with around 30 turning up, it was clear that it would take time for those attending to feel comfortable with one another. Fliss says this was especially the case with the children. The adults on the other hand wasted no time getting to know each other.

From our experience of support groups at **Colostomy UK**, we would say that early meetings being a little subdued is normal.

CONTINUED ON PAGE 35, COLUMN 1

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CONTINUED FROM PAGE 33 COLUMN 3

This is why, at adult support groups, activities like chair yoga or our recently launched Creative Arts sessions can play a vital role as 'ice breakers'. Of course their benefits go much further, but something they do help to do, is get people talking to one another! In essence, support groups evolve over time as people find their voices and decide what they want the group to be. Because the ladies were so attuned to the needs of those attending (both the children and adults) and took on board suggestions they received, Gut Feeling has gone from strength to strength. Meetings are now bustling affairs. The children and young people get to mix with ostomates of their own age whilst enjoying a range of activities. Interaction is encouraged by team games, bingo, team quizzes, crafts and free play. The older children also like to use the pool table and table tennis which is available at the venue. While this is all going on, the parents and carers have the chance

to share and discuss all sorts of issues, from travel, type of bag and helping their child with stoma management, to the challenges of starting nursery, primary school and secondary school. They are also more than happy to buy some raffle tickets, the proceeds from which help to cover the running of the group and the special events they now hold. This year's include: a 'Lion Learners – come and meet the animals' day; a 'No boundaries – football skills' session led by an ostomate; a day trip to Beamanor Hall; and, to round the year off, a Christmas party complete with Christmas jumper competition!

Setting up and running a support group requires effort and commitment. But, as Michelle and Fliss have shown, the rewards are many. Gut Feeling's success is testimony to the vital role it plays in the local community, offering children and adults alike the benefits of peer-to-peer support. The feedback they have received and continue to receive speaks for itself. As one

parent recently said: "I think dealing with children with stomas [is] difficult ...not only for the child but the whole family. We all benefited from meeting up with other families in similar situations, the support group is a real help, answering questions you struggle to ask. We as a family also find it a comfort to talk to parents and discuss problems...[it] also helps my daughter who struggles to talk about things but is able to open up a little when we attend. We would be lost without their love and support around us – can never thank them enough".

If on reading this you have been inspired and are thinking about setting up a group in your area, then we'd love to hear from you. We'll be happy to help and advise you. So don't delay, contact **Giovanni** our Development and Fundraising manager on **0118 939 1537** or email him on: **Giovanni.cinque@ColostomyUK.org**

Written by
Richard Biddle



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.

Ready to take the plunge?



We've had a great response to the three Active Ostomates swimming sessions that we've held so far this year. Things kicked off in April with a swim in Liverpool, followed by Derry/Londonderry a few days later. Our most recent event was held in Leicester in June. Here's just some of the feedback we've received:

"I didn't do much swimming at all but I got in the water and that's what matters, smashing the fears with the help of my wonderful family"

"Today was the first time in 30 years that Mum has had the opportunity to enjoy time with other ostomates"

We're always on the lookout for new venues so please send your suggestions in to Giovanni.cinque@colostomyuk.org and keep an eye on our website for future events.



Get creative!



Members of the new WAMS (Windsor, Ascot, Maidenhead & Slough) support group were amongst the hundreds of people who have taken part in our 'Creative Minds' art initiative this year.

This is the initiative's first full year and so far groups in Guildford, Brockenhurst, Sheppey, Salisbury, Chatham and Gravesend have enjoyed getting creative. Amongst the highlights still to come this year are Glasgow and York.

To find out if we are running a session near you or if you run a support group and are interested in hosting us just call **0118 939 1537** or email Giovanni.cinque@ColostomyUK.org



Congratulations Emma!

Huge congratulations to Emma Rayne who completed the Blackpool Marathon back in April, less than five months after stoma surgery. Emma is aiming to reach Everest next year and you'll be able to follow her journey online at www.ColostomyUK.org and through *Tidings*.

WEBSITE: WWW.COLOSTOMYUK.ORG

#ActiveOstomates

Welcome Debra



This year has seen a massive increase in the number of chair yoga sessions we have delivered. The geographical coverage has expanded considerably too. For the first time there have been sessions in Yorkshire, Lancashire, the North East and the South West of England. On 6 August we are off to Glasgow.

The expansion is partly down to our recent recruitment of a second instructor Debra, who joins Judy as part of our team.

It's also been exciting to see that demand for the sessions has led to us delivering chair yoga at a number of events including open days for Stoke Mandeville and Bristol Ostomy Self support.

If you're part of a stoma support group and would like to host our chair yoga, or would like to find your nearest session email Giovanni.cinque@colostomyuk.org or call **0118 939 1537**.

Developing a physical activity intervention for people who have a stoma



Over the last couple of years we've been closely supporting the University of the Highlands and Island's work on a Bowel and Cancer Research funded project to promote the benefits of physical activity for people living with a stoma.

As part of this, we were delighted to attend an advisory group meeting at University College London, to view a video that's been produced to support the project, and give our input for its further development. For more information online follow [@Stoma_activity](https://twitter.com/Stoma_activity) on Twitter

Rugby League Update



L-R: Oliver Rowley, John Flood, Tim Olaniyan

Our Team Colostomy UK Rugby League season kicked off on Easter Saturday when we played Medway Dragons in Gillingham. See page 26 for more detailed coverage. That was followed by a visit to Chorley Panthers on 1 June.

This year we've secured some great backing from SecuriCare Medical, Pelican Healthcare, Welland Medical, Cheney Payroll services, and Dave Kaye Associates. We've also been lucky to get the support of former England, Bradford Bulls and St Helens star, Paul Anderson, who had a temporary colostomy early in his career. Having Paul on board has led to a noticeable increase in awareness of this initiative and, we hope, awareness of stomas more generally, with features appearing in the Guardian newspaper, Rugby League Express, Forty–20 magazine, and BBC Five Live.

We've got a number of other games in the pipeline this year and are always looking for new players, supporters and helpers. Both men and women over the age of sixteen can play for us so get in touch if you fancy a game! Call **0118 939 1537** or email Giovanni.cinque@ColostomyUK.org



L-R: Paul Anderson and Kaven Ellison



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Norman, 67

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Patient Safety

– Your options when things go wrong

MOORE BLATCH

Ostomates each have their own story to tell, and most have nothing but praise for those responsible for their health care, but sometimes things go wrong. When they do, my many years spent as a solicitor investigating serious clinical errors for the NHS provide a great resource when deciding what advice to give.

For the overwhelming majority of patients, a colostomy, ileostomy and urostomy will be the only and inevitable consequence of illness, but that is not the case for a significant minority of patients. For many, appropriate and timely medical care could, and should, have led to a different outcome.

Delays in diagnosing cancer, surgical errors and delays in treating abdominal infection can all lead to a stoma. Failure to properly diagnose and treat bladder cancer in an adult, or failure to identify occult spina bifida in an infant can lead to a urostomy. Appreciating that a different outcome was possible is often not recognised for some time, or at all.

In recent years learning from errors to prevent harm in health care has taken centre stage. Whether it is the World Health Organisation, the Royal Society of Medicine, the Royal Colleges of Medicine, the General Medical Council or the British Medical Association, the emphasis on learning from error is now accepted. Our own Health Secretary has made this a key objective, recognising that every complaint or claim for compensation, contributes to the creation of data from which our NHS can learn.

Patients that have come to harm as a result of poor care usually want four things: an explanation, an apology, an assurance that lessons will be learned and fair compensation.

The patients I represent cherish the NHS and want it to be the best it can be, demonstrating altruism in the most challenging of personal circumstances.

What options do you have when things go wrong?

If there is an aspect of care which you are unhappy about, the first step should always be to raise your concern with those treating you. Since 2014 the NHS has been subject to a duty of candour and you are entitled to a frank explanation.

You can involve the Patient and Liaison Service (PALS). There is a PALS office at most hospitals and this is usually open during normal working hours. Their service can help address problems when you are using the NHS. If that does not resolve the issue, you can make a formal complaint. Your letter should be polite, focused, succinct and the paragraphs numbered to make it obvious if a particular point is not responded to. Also, make sure you request a written reply.

Although the complaint process may be a useful tool in understanding what went wrong, seeking legal advice straight away may be the appropriate option when substandard care may have resulted in serious harm and/or a life changing physical or psychiatric injury. Redress can only be achieved through making a claim for compensation.

The thought of taking legal action can be daunting. The majority of patients who suffer harm do not seek legal advice, either because they are concerned about the cost or because they simply think they will have no chance against the machinery of the medical profession. Some worry about whether or not making a complaint, or bringing a claim, may adversely affect the care they will continue to need. Although this is an understandable fear, my colleagues and I have never seen this happen.

The cases are often lengthy and complex, so choosing a specialist clinical negligence solicitor is essential. Do not be frightened to ask questions about the solicitor's experience of investigating a case like yours and do not hesitate to ask about the firm's success rate. The best solicitors are familiar with medical experts with a national and often international reputation, many of whom are leaders in their respective fields, who they will retain to work for you.

To successfully pursue a clinical negligence claim it is necessary to prove two things. Firstly that care fell below an acceptable standard and secondly that in doing so injury, or a delayed recovery, resulted.

The process involves obtaining all your medical notes and records, information from you as the patient, the instruction of independent experts and the careful formulation of a letter of claim, to which the defendant is obliged to respond within four months.

Only after this period has expired is it generally appropriate to commence legal proceedings. The overwhelming majority of cases are settled without reaching the door of the court, but the best guarantee of success is intense preparation with the objective of proving each and every allegation that may properly be made, so that it becomes clear to everyone at the earliest possible stage that a settlement must be achieved. The best way to avoid a trial is, therefore, to prepare as if one is on the horizon.

In addition, cases have to be properly funded and the overwhelming majority of clients are assisted with the benefit of a Conditional Fee Agreement (no win, no fee). This is the mechanism through which patients of ordinary means use to be on an equal footing with the other side in terms of financial and medical resources.

There are time limits that must be met to bring a claim.

While there are some exceptions, generally you need to bring a claim within three years of the date you knew, or ought to have known, that an injury might be attributable to an error. In the case of a child, the time does not start to run until they reach the age of 18. However, it is better to consult a solicitor at an early stage before memories fade and any documentary evidence is lost.

Whether you think you have a complaint to make, or possibly a claim, a good solicitor will happily provide free advice as to your likely options, so do not hesitate to seek their legal expertise. ■

Tim Spring

Partner and Head of Healthcare
and Clinical Negligence
Tim.Spring@mooreblatch.com
Tel: 023 8071 8000

Colostomy UK: focus on fundraising



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

Why should you fundraise for Colostomy UK?

Colostomy UK is a self-funding charity. We receive no statutory support and so rely on donations to fund our activities. This means that every penny that you fundraise for us is vital. Without your help, we couldn't support and empower ostomates or be their voice on the bigger issues.

Get involved!

Are you interested in fundraising for us? A successful event doesn't need to raise huge amounts of money. We've got plenty of fund-raising ideas to help get you started. If you would like one of our brand new fund-raising packs, which also include lots of hints and tips about organising an event, then call us on: **0118 939 1537** or e-mail: **fundraising@colostomyuk.org**

Grants and Trusts

Thanks to the following charitable trusts for supporting

Colostomy UK: The Stella Symons Charitable Trust, The Constance Travis Charitable Trust, The Reuben Foundation, The Donald Forrester Trust, HDH Wills 1065 Charitable Trust, The Golden Bottle Trust, the Ganzoni Charitable Trust, and The Pennycrest Trust.

Easy fundraising



Easy fundraising is a website which 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:

www.easyfundraising.org.uk/causes/colostomyassociation/

Thank you!



Clockwise from calendar: Panthers Calendar, Barbara Milleret, Nigel, Charlotte McCarthy, Robert Gale

This year we've been delighted to see not only the different types of people who have been fundraising for us but also all the different ways they've been raising funds and awareness.

Unfortunately we don't have the space to acknowledge everyone so here are just a few of the dozens of you who have been supporting **Colostomy UK** this year:

- ❖ Robert Gale competed in the Wye Valley 10K trail race and raised over **£250**.
- ❖ Richard Hubbard ran the Stockholm Marathon in June raising over **£600**.
- ❖ Barbara Milleret Climbed Snowdon in May and raised nearly **£300**.
- ❖ Charlotte Brown cut off 33cm of her hair and in the process managed to collect **£500!**
- ❖ Nigel Lincoln Dyed his beard blue!! Funds are still coming in for Nigel so we'll keep you updated on how much he raises...
- ❖ Charlotte McCarthy and her Fiancée Jak were involved in a car accident that left both of them with stomas. Rather than have an engagement party they asked family and friends to donate to **Colostomy UK** and raised nearly **£500**.
- ❖ Chorley Panthers Rugby League Club raised nearly **£700** from sales of their naked calendar!
- ❖ The Quiz and Chips evening at St Peters Church, Didcot raised **£410**.

We want your stamps!

WANTED

POSTAGE STAMPS

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





Send your stamps to -

**COLOSTOMY UK
STAMP APPEAL
10 Chestnut Avenue
North Walsham
Norfolk
NR28 9XH**

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

Unity Lottery

unity

It's now been over three years since the Unity Lottery replaced our 500 Club and we are glad to say that not only is its popularity growing with more supporters taking part on a weekly basis, they are also winning regularly as well!

Members have the chance of winning a main prize of £25,000 each week (plus a £2,500 donation to **Colostomy UK**), as well as smaller prizes of five free draws, £25, and £1,000. Entry is only £1 per week and we receive 50p for every £1 ticket sold. You can join by completing the form on page 32 or online by visiting www.unitylottery.co.uk Just remember to link to **Colostomy UK**!

FREEPHONE HELPLINE: 0800 328 4257

Leave a Legacy



WHAT WILL YOUR LEGACY BE?

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

What your gift means

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

- ✿ Ensure there is always a voice at the other end of the phone.
- ✿ Train volunteers to provide support at open days and in hospitals.
- ✿ Fund our campaign for a stoma friendly society.
- ✿ Help support our projects including: 'Active Ostomates' and 'Caring for a Person with a Stoma'.

How to leave a legacy

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

Your solicitor will need the following information:

Name: **Colostomy UK**

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

Charity Commission registration number: **1113471**

After you have provided for your loved ones we hope you will consider a gift to our Charity.

Donate by SMS/Text message

You can donate to **Colostomy UK** by SMS/Text message:

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

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

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

There is no cost to you for sending the message and your free allowance or bundle will not be affected – the only charge will be the donation itself. The amount you donate will be added to your mobile phone bill, or deducted from your pay-as-you-go credit. You will receive a reply confirming your donation.

Fundraising, payments and donations will be processed and administered by the National Funding Scheme (Charity No: 1149800), operating as DONATE. Texts will be charged at your standard network rate. For Terms & Conditions, see www.easydonate.org

Do something amazing!

Join Team Colostomy UK.

Together we can make a difference.

Whether you run 5K, complete a marathon, skydive or swim the channel. Do it as part of Team Colostomy UK!



fundraising@ColostomyUK.org
0118 939 1537

ColostomyUK.org



A different harbour

Rosemary Brierley

When I look back, I see the bowel problems and the resulting stoma as the “storm” that changed the course of my life leading to a different, yet no less fulfilling, harbour.

In my thirties I saw myself staying in the job I loved, until I retired. By my early forties, I knew this was not going to be possible. My employers had kept my job open for two years, while I had emergency surgery for an abdominal abscess, a hysterectomy and two failed rectal-prolapse repairs. I faced further surgery and was forced to take early retirement on the grounds of ill health. I was 42.

I recall the year that followed through a fog of painkillers and sleeping pills. I ended up with a stoma, something I wished the surgeons had created right at the beginning. It wasn't the stoma that stopped me going back to work. That solved the problem: my bowel now worked. The chronic pain was the result of surgery to try and repair the prolapse and avoid the alternative: a stoma. Back then operations were carried out through a large abdominal incision rather than the keyhole surgery we have today. They could result in sections of bowel and other internal organs sticking together as they healed (adhesions) causing more pain with each successive operation. Also, the possible long-term effect of the mesh, used for prolapse repairs at the time, wasn't recognised.

The stoma itself wasn't a problem: no more difficulty in passing motions, no more long periods of constipation. I had made the decision to have it, so the bag itself didn't come as a shock. I wasn't, however, prepared for feeling my stoma discharging as I sat at the table eating my breakfast - but I got used to that. The skin problem I experienced in the early days caused concern as the bag wouldn't stick - I thought I would never go out again! My stoma care nurse suggested irrigation as it would allow me the opportunity to leave the bag off for a while to give the skin chance to heal.

Irrigation gives an ostomate a great sense

of freedom so I am probably one of the very few people who do not continue irrigating once they have tried this method of stoma management. The reason wasn't that the process was difficult or inconvenient, it was just that I had endured so many years of laxatives and enemas that it was reassuring to know that my bowel would work on its own.

I found a bag that was kind to my skin. Now, apart from getting up early so there's enough time for my stoma to work before I go on a long journey, wearing a bag has never made much difference to my life. I just have to make sure that I always have my emergency kit with me, just in case.

Early retirement had never been part of my plan for the future. To cope with the chronic pain and come to terms with it all, I wrote down what had happened to me: the feelings of disbelief, anger, “why me?” and finally acceptance. I discovered I could lose myself, block out the pain with my writing. Those words will never be read by anyone but me, however, they did help me come to terms with what had happened and put all the difficult times behind me.

With more time to spare I was able to help with childcare, so my daughter could go back to work; I really value my time as a hands-on grandma. I also became a volunteer for the BCA, as Colostomy UK was known in 1999, and over the last 20 years, I have met some really interesting and inspiring people. My family saw the part writing played in my recovery and encouraged me to enrol on a creative writing course, and then to move on to a master's degree, which stood me in good stead when I became editor of Tidings.

I also had time to call on my eighty-year-old aunt a couple of times a week and it was during one of these visits that she showed me her diary and told me the secret she had kept for more than sixty years. In a roundabout way, this helped me to overcome my fear of flying. I had listened to those “old wives’ tales”

about bags blowing up on aeroplanes, but to see the places where my aunt was posted during World War II, I had to visit Kenya and Sri Lanka. I discovered that air travel with a stoma presents no problem. Last year I managed to complete my aunt's biography and *A Bletchley Park Wren Overseas* is now listed on Amazon and also available from Waterstones, Foyles and independent bookshops.

If my voyage through life had followed its plotted course, I would be seven-years retired by now. As it is, I was there for my grandchildren as they grew up, have visited places I never knew existed, have written a book, and met some wonderful people along the way. And all this, not despite my colostomy but because of my colostomy.

Rosemary Brierley

A Bletchley Park Wren Overseas



The diary and reminiscences of Flora Crossley who served at Bletchley Park and its overseas outstations in Africa and Ceylon during World War II

Rosemary Brierley

A Bletchley Park Wren Overseas
ISBN: 978-1-9996788-9-0

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

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

Signed _____ Date _____

Signature: _____ Date: ____/____/2019

Signature: _____ Date: ____ / ____ / 2019

News from support groups across the UK



Chester Stoma Support Group 5th Anniversary 14 February 2019

The **Chester Stoma Support Group (CSSG)** was formed by Maria Brown one of our stoma nurses. The group provides advice and support to all those living with a stoma in the Chester area. It is also open to their family and friends; we want the group to be informal and welcoming to patients and their families.

Funded by monthly attendance subscriptions, the group has grown steadily and now has a membership in excess of 40 people. We currently meet in one of the Boardrooms at the Countess of Chester Hospital at 11am on the last Saturday of each month (except December). The format for each meeting is informal and regularly includes refreshments, a raffle and a short talk from various speakers, some stoma related and some of general interest. We also organize regular social events such as afternoon tea on the Chester canal, fish and chip evenings, quizzes and a Christmas lunch.

As a group we may have had different illnesses and journeys, from patients still on the ward only days post op to members who have had their stomas for over 10 years, but the over riding purpose of our often lively meetings has always been and will continue to be that of companionship. We get to know each other, help and advise each other and, if needed, support and comfort each other. Many of us have quite unexpectedly forged new and firm friendships through these meetings.

Historically, we have donated equipment such as individual patient fans to our linked gastro ward at the Countess of Chester Hospital. Moving forward, we will be helping to raise funds for national and local charities. Some of our members have already taken part in sponsored walks for our medical wards and are planning to take part in the **Colostomy UK's** 50K event later in 2019.

If you are interested in joining us, or would like to be included in the group email of our monthly minutes, (which include details of our upcoming events), please contact Maria Brown, stoma support nurse on **01244 366 170**.

CONNECT: A social group for ostomates and their families in the Harlow and district area.



In early April, members of Connect were at the entrance to the Princess Alexandra Hospital (Harlow) with members of the hospital stoma team, Macmillan, hospital staff and hospital volunteers. They were all there to hand out pamphlets and chat to visitors to the hospital about bowel cancer awareness. The event was organised by the hospital stoma team. Pictured above are Alan Marshall and Alan Benton of Connect, resplendent in the 'Stop the Poo taboo' t-shirts.

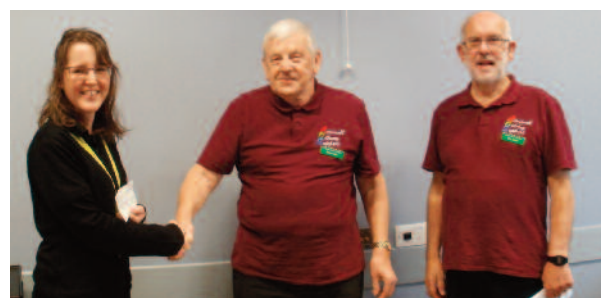
Ed's comment: Well done to everyone involved, to read more about Colostomy UK's campaign to fight the 'Poo Taboo' visit our website: www.ColostomyUK.org You'll find all our current campaigns under the 'Get involved' tab.

Report on donation to the Cornwall Air Ambulance



On Tuesday 26 February representatives from Cornwall Ostomy Support were proud to present a cheque for £1000 towards the purchase of the new helicopter needed by the Cornwall Air Ambulance. Cornwall Ostomy Support are a group who provides advice and social support for anyone in Cornwall with over 170 members with some form of stoma and can be contacted www.cornwallostomysupport.org.uk

For more information please contact Ken Jones on **01872 863 106** or email: kenjones1808@gmail.com



If you would like to set up a support group in your community or if you're interested in volunteering please email info@ColostomyUK.org or call us **0118 939 1537** and speak to Giovanni or Libby.



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 Colostomy UK, IA and Urostomy Association stands.

Colostomy UK volunteers, who all have stomas themselves, attend stoma care Open Days all over the country whenever possible. Do come along, call at our stand and have a chat.

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

CliniMed Event

Tamworth Football Club,
The Lamb Ground, Kettlebrook Road,
Tamworth, Staffordshire, B77 1AA
13 August 2019 10:00am–12:00noon
T: CliniMed: 0808 1596 017

Royal Lancaster Infirmary Stoma Care Open Day

Ryelands House, Ryelands Park,
Owen Road, Lancaster,
Lancashire, LA1 2LN
10 September 2019 1:00pm–4:00pm
Stoma Care Department

Patient Awareness Day

Bridge Community Church,
Rider Street, Leeds, LS9 7BQ
26 September 2019 9:30am–3:00pm
Continence, Urology and Colorectal
Service: info@cucs@nhs.net



Tell us of your open days to include them on our website and in the next issue of *Tidings*.

Contact Colostomy UK, e-mail your contact details to:
info@ColostomyUK.org

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

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 240253
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 00 00
Monday–Friday, 9am–8pm

Crohn's and Colitis UK

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

The IBS Network

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

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

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

Stoma support groups in your county

Channel Islands

Guernsey

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

Jersey

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

Isle of Man

Isle of Man

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

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 Giovanni:
info@ColostomyUK.org or call on 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
Clare Hall telephone 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
Carla 07846 354 918
e-mail: carla_wright@sky.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
East Cheshire Stoma Support Group
Catherine McIntosh: 01477 535 071
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'Donnell: 01287 284 113

Co. Durham

Bishop Auckland Stoma Care Group
Mrs Maureen Davison tel: 01388 818 267 email: trebornosivad@tiscali.co.uk
Darlington Support Group
Margaret Clothier, Tel: 0191 333 2184
Durham Stoma Support Group
Lynn Ridley, Tel: 0191 333 2184

Cornwall

Cornwall & Plymouth Bowel Cancer Support Group
The Secretary: 01872 241 145, cbcsinfo@gmail.com or website www.cornwall-bowel-cancer-support-group.co.uk
Cornwall Ostomy Support
Ken Jones: 01872 863 106 or www.cornwallostomysupport.org.uk
Lanhydrock Ostomist Group
Mandy Rowe: 01726 832 642
E: murphy.rowe781@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
Stoma Support Groups in North Cumbria
Stoma Care Nurses 01228 814 179
Stoma Support Groups in North Cumbria
Stoma Care Nurses 01228 814 179

Derbyshire

Diverted Local Stoma Support Group
Diana Manning: 01283 541 311
F.I.S.H.Y.S. (Friendship, Information, Support & Help for Young Ostomates (age 18-45)
Email for more details:
fishysderbyshire@gmail.com

Devon

Devon IA
Martin Hornby: 01458 251 095 or email: devon@iasupport.org
Mid Devon Ostomy Support Group
Janice - janice234ford@gmail.com or tel: 0792 3975051 or 01884 799369
Plymouth & District Bowel Cancer Support Group
Wendy Wilson - Facebook: Plymouth Bowel Cancer

Dorset

Colostomy Urostomy Pouch Ileostomy of Dorset - CUPID (Bournemouth)
Beryl Andrews 01202 483 303
Colostomy Urostomy Pouch Ileostomy of Dorset - CUPID (Poole)
Jenny Pipe: 01202 740 440
Colostomy, Urostomy, Pouch & Ileostomy of Dorset - CUPID (West Dorset)
Colin Clare - 01305 853 238

Essex

Connect
Lin Hart 01279 505 273 email: comeconnectwithus@gmail.com
Mid Essex Stoma Support Group
Paul Foulger: 01245 224 374
N.E.S.S (North Essex Stoma Support)
Brian Waller- 01206 540 449



Optimistic Ostomates
Angela Taylor 01702 385 510

Redbridge Ostomists Club
Stoma Nurses - Chris/Lisa:
020 8970 8321

STEPS - Stoma Essex Patients Support
01268 451 937 or email-
stepsessex@gmail.com

Hampshire

Replummed stoma support group
www.replummed.me

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

For information tel. 07527 707 069 or
solentostomates@hotmail.co.uk

Southern Ostomy Group

Caroline or Karen on: 07756 819 291
southernostomygroup@hotmail.com

The Hampshire Ostomates Support Group

Contact Nicki Beare on 07771 558 458
or Nichola0405@yahoo.co.uk

Waterside Stoma Support Group

Hazel Derham: 023 8089 1934 or
hayjuder@sky.com

Wessex Urology Support Group

Mrs Jo Stacey: 07910 786 978

Herefordshire

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

Ostofriends Support Group

Peter Lannen ofstofriends@gmail.com
07501 137 511

Stevenage Ostomistics

Judy Colston: 01438 354 018/
neilcolston@btinternet.com

Isle of Wight

Optimistics

CNS's Sarah Capon & Sarah Varma
01983 534 009

Kent

Ashford Stoma Support Group
Carole Hobbs: 01303 814 014

Atoms Support Group

Maria Culleton, SCN: 01227 769 679
or 07827 997 424

Dartford Ostomy Group Support (DOGS)

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

Dover Stoma Friends Group Support

Julie Bell/Ros Marshall: 01233 616 646
and Support Group Organiser June
Golding: 01304 822 696

GOGS (Gravesend Ostomy Support Group)

Tracey: 07779 155 846
or Helen: 07710 780 958

M.O.G.S (Medway Ostomy Group Support)

Tracey: 07779 155 846;
Helen: 07710 780 958
or email mogs-uk@hotmail.co.uk

Maidstone Stoma Support Group
Judy/Kirsty: 01622 224 305

Sheppey Ostomy Group Support (SOGS)

Shelley 07714 734 194/
sogs-uk@hotmail.com

SWANS Stoma Support Group - Swanley

Heather - 07711 445 312
heather601@virginmedia.com

Thanet Stoma Buddies Support Group
Kathy 01843 291 825

Tunbridge Wells Stoma Support Group
Cathy Chitty/Mags Donovan
01892 632 323

Lancashire

Kangaroo Klub, Blackpool stoma support group

For further details please contact the
stoma department at Blackpool
Teaching hospitals, Tel: 01253 956 620
or e-mail

crc-stomanurses@bfwhospitals.nhs.uk

North Manchester and Bury Stoma Support Group

Julie Meadows (SCN) 0161 720 2815
or 07774 263 563

Oldham Stoma Support

June Wilde: 0161 312 5538

Phoenix Bowel Cancer Support Group

Sandra Peet: 01772 683 790,
www.phoenixgroupbvh.com
or eMail: sandrapeet7@aol.com

Leicestershire

Kirby Ostomy Support Group.

Colostomy, Ileostomy and Urostomy in Leicestershire

Janet Cooper: 07464 957 982/
kosg2013@btinternet.com

Lincolnshire

Friends East Coast Support Group

Betty Williams - 01205 724 120,
Sheila - 01205 364 493

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)

For further details please
ring 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

Sarah Varma: 020 8235 4110

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@northumberlandcancersupp
ortgroup.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

Christine Bryden 07757 911726

or e-mail: countystoma@yahoo.com

Outlook The North Staffs Ostomy Support Group

Maira 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

SUPPORT

Normandy Colostomy Support Group
Marina Harkins: 01483 233 126
or 07852 554 049 or Jackie Sanders:
jackie-sanders@hotmail.co.uk
or 07815 603 742. Website:
<http://www.normandystomagroup.wordpress.com>
Stoma Support Group
Robin Young: 01428 723 255

Sussex

Brighton & District Support after Stomas (SAS)
Sylvia Bottomley: 01273 554 407
Chichester Stoma support Group
The Stoma Care Team 01243 831 527
The Ostomy Friends Group
Jane Quigley: 01323 417 400 ext 4552
West Sussex Princess Royal Stoma Support
Tina Walker: 01444 441 881 ext 8318

Tyne and Wear

Gateshead Stoma Patient and Carer Support Group
Stoma Care Nurses: 0191 445 3152 or email stuart.sutcliffe81@yahoo.com
NHS Molineaux Centre
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 email: micheledowney@outlook.com

Warwickshire

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

West Midlands

Coventry Stoma Support
Martin - 07947 385 643

Wiltshire

Swindon IA
www.swindon-ia.org.uk
Wessex Stoma Support Group
Michael Slater:
wessex.stoma@yahoo.co.uk or on
01722 741 233
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 4325 28 or Celia Utley (Chairman) 01226 284 262
Behind You (Calderdale & Huddersfield Bowel Cancer Support Group)
Stoma Care Nurses: 01484 355 062
Bottoms Up (for urology and colorectal cancer patients)
John Whelpton 07974 657 146
email: midyorks.bottomsup@gmail.com
Bradford Stoma Support Group
Please get in touch with Lisa Hall on
07552 276 747

Dewsbury & District Stoma Support Group

June 07884 003945 or email
dews.ssg@gmx.com
Hambleton and Richmondshire Ostomy Support Group
Stoma Care Nurses - Judith Smith and Mary Hugil 01609 764 620 / 07736 295 131

Harrogate Stoma Support group
Stoma department office Nurse Gill Wilson/Fiona Holtham 01423 555 786

Leeds Bowel Cancer Support Group
Lynda Castle (Colorectal Nurse Specialist) 0113 206 5535

Scarborough Stoma Support Group
Stoma Care Team: 01723 342 388

The Hull and East Riding Colostomy Support Group

Pete Smith: 07989 565 335 or Pete Rennard: 07939 518 642 /
01482 793 966 or Rosanna Grimsby:
01482 801 575. www.hercosg.org.uk

Northern Ireland

County Antrim

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

County Armagh

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

County Down

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

Londonderry

Causeway Support Group
Mary Kane: 028 7034 6264

Republic Of Ireland

County Mayo

Mayo Stoma Support
Marion Martyn: +353 94 902 1733

Dublin

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

Scotland

Ayrshire

Ayrshire & Arran Stoma Support Group
Jim Krasewitz: 01292 220 945
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:
shirleyjones78@gmail.com

Bridgend

Bridgend Ostomy Patients Support Group
Anita Brankley (Secretary) 01656 645 602 or 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 532473

Powys

The Bracken Trust Cancer Support Centre
Helen Davies: 01597 823646

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



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Ostomy Female underwear: Shortie or brief with built-in internal support left, right or twin pocket with night drainage. Sizes 8-24. Colours: black or white



Unisex seamless support briefs, providing appropriate light post-operative support. Sizes S/M - 2XL/3XL. Colours: white, beige or black



Female seamless support briefs, providing appropriate light post-operative support. Sizes S/M - 2XL/3XL. Colours: white, beige or black



Ostomy Male underwear: Trunks with built-in internal support left, right or twin pocket with night drainage. Sizes: Small - XXL. Colours: navy or denim



Ostomy Male underwear: Boxers with built-in internal support left, right or twin pocket with night drainage. Sizes: Small- XXL. Colours: navy or white



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stoma