Autumn 2018 | Issue 51

Supporting and empowering you

Colostomy UK

Tidings

Who says you can’t play rugby league with a stoma!

50K CHALLENGE

Team Colostomy UK RL takes to the field.

page 28

“Tackling the stoma stigma”


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1. Coloplast, Product Evaluation, Global Sensura Mio product evaluation results 2016, Data on file (VV-0197319)
2. Møller Kruse T, Marian Størling, Z. Considering the benefit of a new stoma appliance; a clinical trial. British journal of Nursing, 2015

Dear readers

Cover picture
Kaven Ellison from Team Colostomy UK Rugby League.

Introducing Team Colostomy UK Rugby League Team

Usually it's around this time of year that we look back at the summer and moan about the awful weather we've had. Well, we can hardly do that! Although (of course) we are both far too young to remember, we have been told that it was comparable to 1976…In fact the heat this summer called for extraordinary measures. For me (Libby) this involved getting out the paddling pool. But I couldn't compete with Sarah, who travelled all the way to Las Vegas to cool down – on a zip wire over Bootleg Canyon!

Despite the inevitable slowdown with people away on holiday, we have remained busy at **Colostomy UK.** There have been further developments on the airport front. We also attended a number of conferences for healthcare professionals. You can read more about these on the Bulletin Board. The 50K challenge has continued to inspire people and, as I write this, the target is tantalisingly close to being reached. The summer also saw Team Colostomy UK's Rugby League team make its debut against the Medway Dragons Masters, check out the Active Ostomates page for more.

We have two articles on reversal surgery in this edition. The healthcare professionals' 'lowdown' is provided by Jennie Burch, in a piece packed with useful information and advice. The picture is then completed by Xenia Standbridge's story. This gives a patient's perspective from somebody who has recently undergone the surgery. As always, our Real Lives' stories are worth a read. Pamela Wickham recounts how a freak DIY accident led to emergency stoma surgery. Marion Berekis provides a shining example of staying positive when events seem to conspire against you, while Dennis Pilmoor talks about why, years on from having his stoma, he decided to become a volunteer for **Colostomy UK.** Jackie Dudley and Duncan Wells (both of whom are on the editorial board) pick up on various aspects of travelling with a stoma. Jackie talks about how she built her confidence going 'out and about' by taking small steps at first, while Duncan talks about the importance of preparing for travel (whether this be by plane, train or automobile). This time round we don't have a dear Nurse section. As we only received a couple of questions for this edition, we decided to hold these over until the next time and give Julie a well–earned break!

Finally, with the Winter edition of *Tidings* not due to hit the doormats until early January, we'll sign off by wishing all our readers a happy Christmas!

Libby

Libby Herbert
General Manager

Sarah

Sarah Squire
Trustee, Colostomate and Volunteer


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Contents

We are **Colostomy UK.** Here if you have questions, need support or just want to talk to someone who lives with a stoma.

Your voice on the bigger issues: advocates for your rights and campaigning to raise awareness of what matters to you; running projects to empower you; building communities to support you.

How to contact us

General Enquiries
0118 939 1537

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Cover story

Colostomy UK news

Real lives

Wellbeing

Fundraising

Support

New products

Donating to Colostomy UK

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

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

Bulletin board

Richard Biddle
Writer and Researcher
E: Richard.Biddle@ColostomyUK.org

Your voice on the bigger issues

Read on for a round–up of all the latest news on our campaigns and advocacy work.

The Association of Coloproctology of Great Britain and Ireland (ACPGBI) and the Association of stoma care nurses UK (ASCN)

In July Giovanni Cinque (Fundraising and Development Manager) and Sarah Squire (trustee and volunteer) attended the ACPGBI international convention in Birmingham on behalf of **Colostomy UK.** This annual event brings together colorectal surgeons from across Great Britain and Ireland. More recently, we were delighted to be asked to speak at the ASCN annual conference in September. We gave three talks. Ian Jackson (trustee and volunteer) and Sarah Squire spoke about the challenge of raising public awareness about stomas. Giovanni Cinque and Peter Martin (trustee) explained how we are encouraging people with stomas to stay healthy through **Colostomy UK's** Active Ostomate project. Richard Biddle talked about dementia and a stoma and the work we have been doing in this area with Dementia UK. As you would expect, surgeons and stoma care nurses are very protective of their patients. Attending their annual conferences is a great way for us to give them the confidence to recommend and signpost people with stomas to **Colostomy UK.** ■

Airport updates British-Irish airports expo

Our work with the Civil Aviation Authority (CAA) and airports across the UK has continued to gather momentum. In June, the CAA invited us to attend the third British–Irish Airports Expo in London. Libby Herbert our General Manager, Clare Matthews our Marketing and Communications Manager and Richard Biddle our Writer and Researcher went along. It was very evident that the issue of travellers with hidden conditions is now firmly on the agenda. Indeed, a whole floor of the venue was given over to the CAA's 'People with Reduced Mobility and Airport Accessibility Conference'. As well as being able to contribute to this and be a voice for ostomates, we were also approached by representatives from a number of airports, seeking our help with staff awareness training. ■

A big thank you!

Back in July Libby visited Wessex Stoma Support group in Salisbury where she was thrilled to be presented with a donation of £1,000. Ken Edwards, the group's chairman, explained that this was in recognition of **Colostomy UK's** campaigns and projects. We like to thank everyone for their generosity. Donations, big and small, are vital for our ongoing work! ■

Our 2019 Open Day

As we mentioned in the last edition, we've started planning our 2019 Open Day. Spring might seem a long way off, but you would be surprised how quickly good venues get booked! Although we can't reveal the location yet, we have ensured that it is geographically central and easily accessible. We are also starting to put together the day's agenda and would like to thank those who attended our 50th Anniversary celebration in September 2017 for all the suggestions and feedback they gave us – it's proving very useful! ■

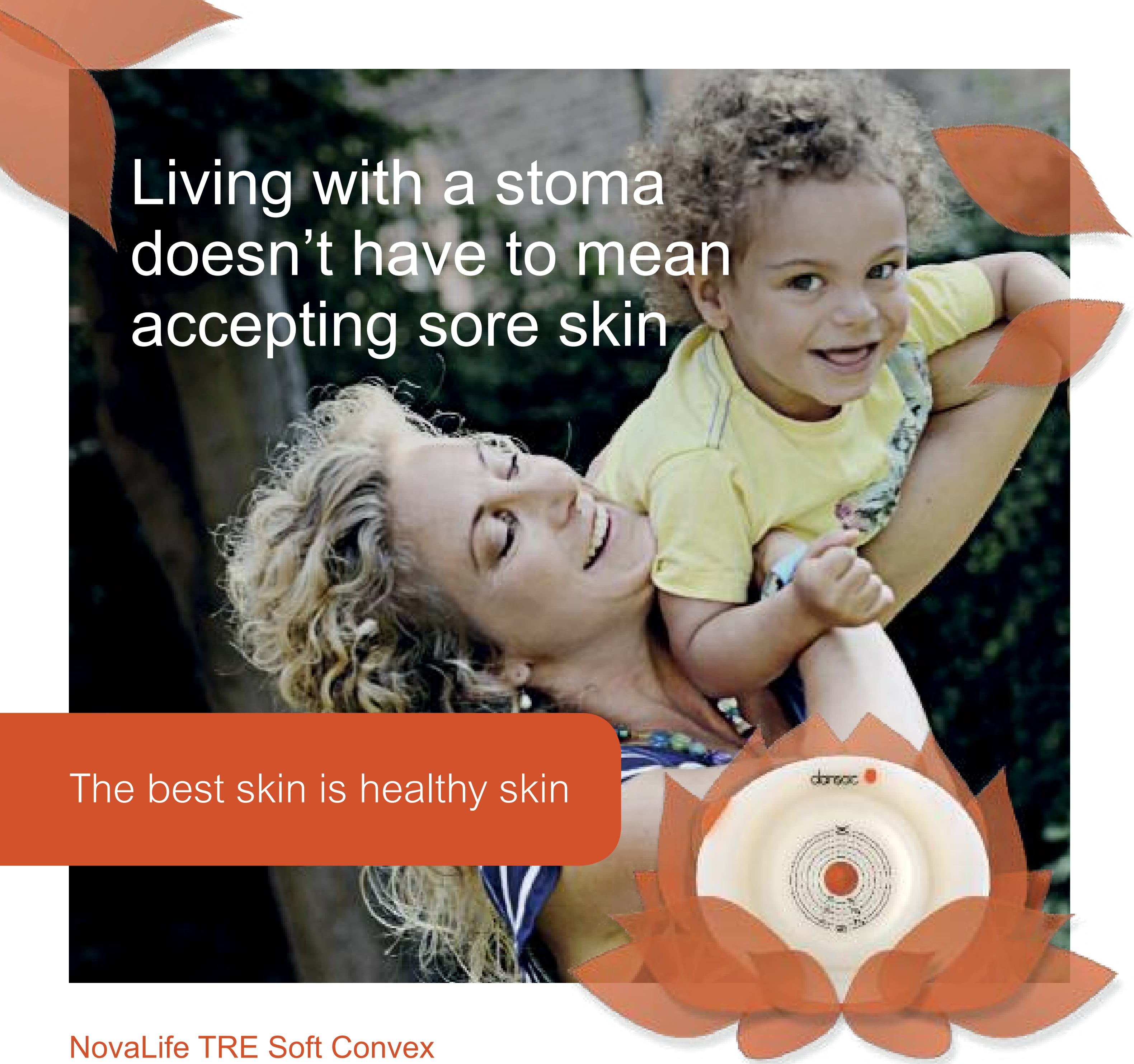
Recognising long–standing volunteers

Colin Allum has been a **Colostomy UK** volunteer for almost a decade now. As he lives near to our offices in Reading he visits every Wednesday and spends the day doing just about anything that we throw at him, from general office admin to answering the helpline. To show our gratitude we put Colin forward for the annual Reading Voluntary Action awards. Colin attended the awards ceremony along with his wife and Jo McKenzie (Senior Support Co–ordinator) and Libby. It was a good evening, made all the better because Colin was recognised for all his hard work.

We also want to say a huge thank you to Bob Broadhead. Having reached the age of 83 this year Bob has decided to retire as a volunteer. He started with us in 1983 back in the days when we were known as the Colostomy Welfare Group and were based in London. Over the past 35 years his contribution to the charity and the support he has given fellow ostomates in the Hampshire area has been incredible. The list of things he has done includes attending and talking at conferences and open days and giving his input to stoma workshops organised as part of the training for postgraduate pharmacy students. In 1996 he completed the Vauxhall Four Peaks Challenge, raising over £5,000. He also ran the London Marathon in the same year. Everyone at **Colostomy UK** sends Bob their best wishes and hope he enjoys the gift we sent. ■

Heathrow experience and engage day

Are you worried about going through an airport and flying with a stoma? Heathrow's Experience & Engage events give you the opportunity to experience a journey through the airport. Libby went to one on 14 July and found it very worthwhile. The 'journey' started in the car park and then went through every step right up to boarding the aeroplane. This included finding special assistance (for those that require it), going through check–in and then through security. More dates are planned (at time of going to print, we understand 11 October is next). If you want to go along you need to book, as places go quickly and are on a first come, first served basis. Please contact us to find out more. Likewise, if you have any fears about going through an airport and want to chat through these, don't hesitate to get in touch. ■


Living with a stoma doesn’t have to mean accepting sore skin
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Stoma reversal

Jennie Burch

Jennie Burch
Head of Gastrointestinal Nurse Education, St Marks Hospital

People have stomas for different reasons. For some their stoma will be permanent, others might have the opportunity of a stoma reversal.

What is a stoma reversal?

A stoma reversal means that a temporary stoma is removed or closed. This means that bowel waste (stool and wind) will pass again from the anus.

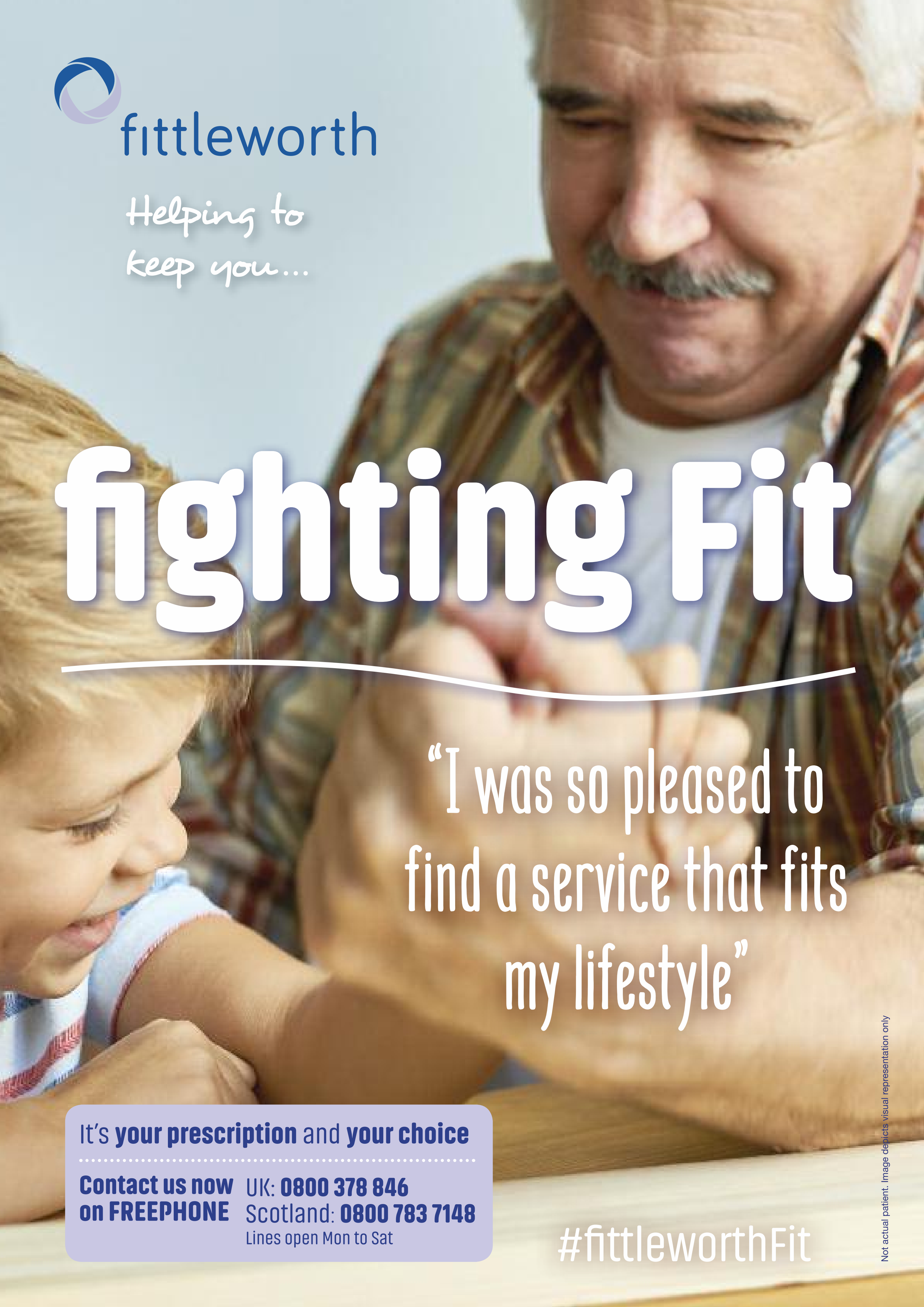
How is a reversal done?

Reversing a stoma requires an operation and a few nights in hospital. The operation often takes less than an hour, which is far less time than it takes to form a stoma. The surgeon cuts around the stoma on your stomach. If you have a loop stoma the two ends are re-joined using stitches or staples and put back inside of your tummy (abdominal cavity). If you have an end stoma, the stoma will be re-joined to the other part of your bowel. The hole where your stoma was will be made into a small wound. This heals over a few weeks. Some people need to have a bigger cut on their tummy, often in the same place as the scar from their stoma surgery. This wound is bigger and takes longer to heal. While the wound is healing and for a few weeks afterwards it is essential not lift anything heavy that may weaken the wound and put you at risk of developing a hernia. Speak to your doctor or nurse for more advice.

Why do I need to stay in hospital for a few days after the reversal?

You will need to be in hospital until the doctors are satisfied that you are well enough to go home. In most hospitals this is about 3-5 days. There are a few centres where the length of time you are in hospital is less. Either way, if there are problems and the doctors do not feel you are well you will be kept in hospital for longer.

CONTINUED ON PAGE 13, COLUMN 1



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CONTINUED FROM PAGE 11, COLUMN 3

Before you go home it is important that you feel ok and tests such as blood pressure are stable and satisfactory. You need to be able to eat and drink without problem; you might have to eat small, frequent meals initially. Your bowel usually needs to be working for wind and solids too. You are often given a laxative to ensure that this happens. You need to be able to walk and not be in too much pain. Paracetamol is often all that is needed to keep pain under control once you are ready to go home.

Things to consider

It is not possible to reverse a stoma for all people. People who might be able have a reversal include people with an ileostomy and an anterior resection and people who underwent a Hartmann's procedure and a temporary colostomy.

If your surgeon discusses stoma reversal there are many things to consider.

Do you feel up to another operation?

Some feel that although they would prefer not to have a stoma, undergoing surgery to reverse it is not something they wish to embark on, now or perhaps ever. While some people struggle to live with their stoma physically and/or emotionally, they often find this improves over time and with the help of friends, family and support groups. Even though you might have been told your stoma is temporary, it is made to last. So, if you choose not to have a reversal your stoma won't need to be changed. Likewise, if a reversal is possible, you can delay this until the time is right for you.

Bowel function after a reversal

Bowel function after a reversal is a hugely important consideration. After bowel surgery the bowel function will never be the same. If part of the bowel is removed things inevitably change. If, for example, the rectum was removed either partially or totally then it will be unable to function as it did before your stoma was formed. The role of the rectum is quite complicated; it is an amazing part of the body. In basic terms the rectum (back passage) is the last part of the bowel and has the job of collecting faeces and wind. Once the faeces and/or wind is collected, the rectum sends a message to the brain to let it know there is something that can be passed. The brain then determines if it is possible to open the bowels. If it is possible, then you go to the toilet and pass whatever is collected. If, however, it is not possible to go to the toilet (maybe you are busy or not near a toilet), the brain tells the rectum to hold on for a while. The rectum responds by pushing whatever has collected back a little so that you do not keep having the urge to go to the toilet and will remind you again some time later. If this system does not work well faecal incontinence can occur.

Urgency and frequency

If all or part of the rectum was removed when your stoma was formed then this will leave you with less storage capacity after a reversal. This can lead to problems with 'urgency' and 'frequency'. With the former, the sensation is felt to pass something out of the bottom but the brain cannot tell the body to wait as the urge is too strong and the person has to get to a toilet quickly. If this is not possible incontinence can occur. This is called urge incontinence. The other issue with less storage capacity is that only a small amount of stool can be stored in the rectum and only small amounts are passed each time the bowels are opened. This can lead to frequent toilet visits in a short space of time (often in the morning), to pass small amounts of stool. Some people report both urgency and frequency in relation to passing a bowel motion. The doctor or stoma nurse should be able to advise you if you are at risk of urgency and/or frequency after your stoma reversal. There are ways to manage these problems and for most people the symptoms improve over time.

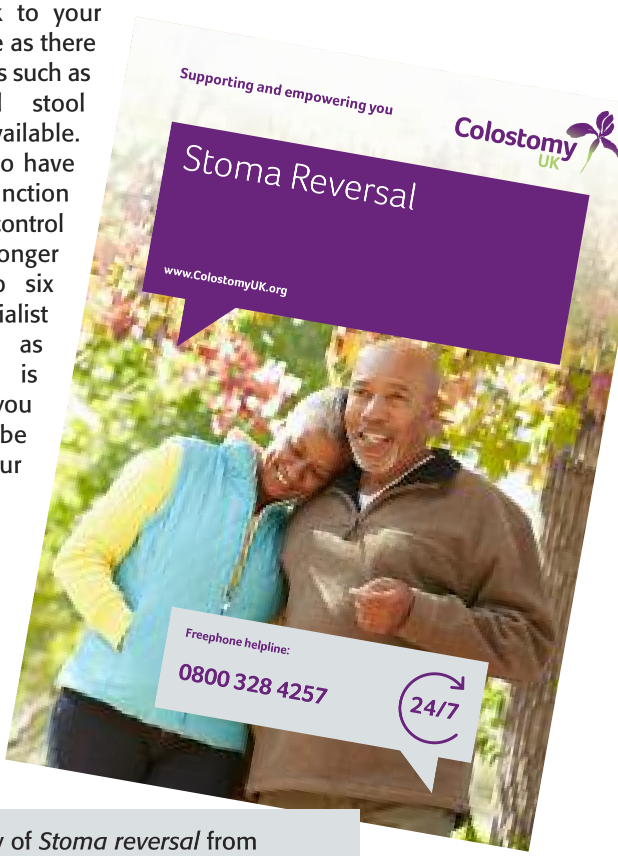
Incontinence

Another problem that people worry about is not being able to control their bowels after a reversal. Bowels are controlled by your anal sphincters, a tight band of muscles that release to allow faeces and wind to leave the body. Anal sphincters are not a glamourous part of the body but they are very clever. Anal sphincters can determine the difference between gas and solids and let out gas without releasing any solids for example. If there is damage to the sphincters they may not work properly. Similarly, if they haven't been used for a while (such as when you have a stoma) they can become weaker, like any muscle that lacks use.

Depending on your circumstances it may be necessary to undergo tests on your sphincter muscles to make sure that they are working well enough for your stoma to be reversed. Most people however, if they had good control of their bowels before the stoma was formed, are likely to also have sphincters that are suitable for stoma reversal after surgery. Sometimes people exercise their sphincter muscles in preparation for their reversal or after the reversal; ask your doctor or nurse if this is suitable for you.

Post reversal problems

If you encounter problems with your bowels after a reversal there are a few things you can try. If your bowels are constipated consider drinking a little more fluid (about 3-4 pints per day of non-alcoholic drinks are recommended for most people) or a little fruit juice. Alternatively increase your mobility and walk more or add more fruit, vegetables and fibre to your diet. If your bowels are too loose and difficult to manage, try having less fruit, vegetables and fibre to thicken up the stool consistency. If you cannot resolve problems yourself speak to your doctor or nurse as there are medications such as laxatives and stool thickeners available. For people who have poor bowel function and/or bowel control that lasts for longer than three to six months, specialist therapy such as biofeedback is available, but you need to be referred by your doctor. ■



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Sarah Squire
Trustee and Co–Editor
E: Sarah.Squire@ColostomyUK.org

This snap was taken last year when members met up in Glasgow.
In case you are wondering…part of the meet–up involved having a go at Tai chi (thanks Coloplast). This is us showing our moves!

Join Colostomy UK's closed Facebook group

The Colostomy UK Closed Facebook group is amazing! That may sound a rather dramatic statement, but on a daily basis I am astounded by the group and its members.

Set up in 2009, we changed the group status to 'closed' in 2012, which meant only members of the group could see posts. Let's face it, we don't necessarily want all of our Facebook friends reading posts about poo. The added privacy means members can talk openly and freely about any issues they have, safe in the knowledge these conversations stay within the group. It has been quoted that as of early 2018 Facebook had more than 2 billion monthly users – wow! So with so many of us using it in our daily lives it seems sensible to use social media as a form of support too. And what amazing support it is. Our group has grown from 250 members in January 2012 to over 6,000 by the end of June 2018. We have members from all over the world and according to group statistics there is not an hour of the day when the group is inactive. As soon as a new member joins, an Admin welcomes them, followed by numerous welcomes from existing members. People may arrive with a specific problem or they may be pre op and terrified. We also have partners, carers and parents of ostomates who join to help their loved ones.

We only offer experience based advice – any medical advice should always come from a health professional. But for many of us, to speak to someone who KNOWS, someone who has BEEN THERE and can offer practical suggestions to problems, is priceless. And social media is fast, very fast. Our members are incredible and can reassure each other within minutes that the problem they are experiencing is common, or they found this or that helped. You can almost feel the relief when someone who joined with a problem has it is solved almost immediately.

I can't pretend we are all best friends; in a group of over 6,000 you would hardly expect this! But I have genuinely made friends for life on the group and disputes are rare. I have been lucky enough to meet some lovely members at the face–to–face meetings we occasionally arrange. Others who I've only ever met online, still feel like old friends. It's not all doom and gloom and leaky bags either. Of course, the very nature of a support group, means that people ask when they are having problems. But these same people are also the first to tell newcomers (especially those pre op) that life with a bag can be great. We also encourage off topic posts. It can be very uplifting to have a joke and a laugh and we believe this is an important part of support too, so we encourage a mix of posts. We all celebrate and commiserate together. It feels like a family and the members make the group the huge success it is. I am very proud to be a part of it.

If you would like to join the Facebook group, search for 'Colostomy UK Support Group' on Facebook, choose the group and you will see a tab to click to join. Once you've requested to join, one of the Admins will greet you. We look forward to seeing you there! ■

Readers' writes

Your letters and emails

Dear Editor

I've been irrigating for about nine years following surgery for bowel cancer in 2008, which resulted in a permanent stoma. As those who irrigate will know, the plastic tubes and bags used for irrigation gradually become stained because of bacteria in the water. This occurs even though the appliances are kept scrupulously clean, resulting in their disposal every four months or so.

In an effort to reduce waste, I purchased a bottle of Milton sterilising fluid, which is suitable for baby accessories, and soaked the affected items in a weak solution whenever they began to show signs of staining – usually after six–eight weeks' use. You might be interested to know that, after treatment, all the plastic items looked sparklingly clean once again, almost as new. This must surely reduce costs to the NHS over the long term if adopted by more of us. The added spin off is less plastic to be disposed of. I will certainly continue to clean my appliances in this way and see how long they last before being replaced.

Jim Arkell

Dear Editor

I cover my filter with the sticky 'blob' provided, then if my pouch inflates I pull back the material on the outside exposing the round hole of the pouch exit and 'burp' my pouch – simples!

Name withheld

Dear Editor

I commend HJB's letter (Summer Issue) about his DIY method of dealing with ballooning. I have had my colostomy now for nine years and, like him, in the absence of authoritative guidance on the subject, I have had to devise my own system for dealing with the problem. My method is very similar to his. Controlled ballooning is an important and seemingly neglected feature of stoma management for those using a closed pouch. Not only does it deal with potential detachment of the pouch when there is an excess accumulation of gas; it also helps to avoid the contrary risk of leakage through pancaking. This can happen when there is insufficient gas to keep the walls of the pouch from sticking together, thereby causing output pressure either to detach the pouch or create leakage beneath the flange. In addition, careful control confers a huge dietary advantage on the colostomate by enabling freedom of choice from a wide range of foodstuffs other than those primarily of the non–gas–forming variety.

My own method differs slightly from HJB's. Having placed a seal on the filter when putting on a fresh pouch, I then ensure that there is at least a little air in the bag; some recommend putting a screwed–up piece of toilet paper in the pouch to achieve this. After that I leave the seal in place throughout the day. When ballooning occurs, it is then only necessary to repair to the loo, or some discreet corner, and release the gas by raising the seal and pressing gently to expel the excess gas. In doing so I take care not to press too hard as otherwise too much force might create leakage through the flange. Then I re–seal the filter using the same seal, taking care to leave a small amount of gas behind to avoid the possibility of pancaking. I generally find a single seal can be used several times a day, but as a precaution I carry a spare sheet of seals in my emergency kit in case of need. It is not clear to me why HJB chooses to make a fresh incision in the pouch and seal it each time. Personally, I have never found this necessary as modern filters are efficient and can perfectly well be re–sealed.

When I first had my colostomy, my induction session only referred to filter seals in the context of their use to prevent water entering the pouch during bathing, showering or swimming – or as a means of avoiding the emission of unpleasant odours in social settings. I dare say that advances in filter design since those days have led to some stoma support teams embracing the wider use of filter seals in their briefings. But it is puzzling that there seems to be no authoritative guidance–sheet on the subject routinely available for handout to those new to colostomy management. Surely this is overdue?

Michael Ward

Your magazine – Your story

We want to hear from you.

Letters and e–mails to the editor are welcome, but we also want your stories and anecdotes. Perhaps something in *Tidings* has inspired you? Or maybe you've noticed something that has a bearing on one of campaigns or projects? And then there's hints and tips for ostomates, we want to hear these too…and so do our readers. Don't worry if writing isn't your thing, because we can do this with you. So don't delay, drop us a line, send us an e–mail, or give us a call and we will take it from there.

Email to: **editor@ColostomyUK.org** or write to: **The Editor, Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA.**

Dear Editor

For more than 40 years I have irrigated my colostomy and, although it is time consuming and a nuisance, after 40 years it is part of my daily routine. I am always determined to conquer any ongoing problems following the extensive surgery I had in 1978 to remove my awkwardly–placed malignant tumour. I still have lymphoedema which has resulted in a severe problem with walking, a colostomy and now an annoying urine situation.

In May I saw my GP and asked for a referral to explore the possibility of self–catheterisation as I was finding it increasingly difficult to live with the urine problems I was experiencing. I had the largest and most absorbent pads issued by the NHS but was not finding the four–a–day allowance adequate. I was constantly wet and was worried about leakage much of the time.

One of the bonuses of self–catheterisation is that drinking is to be encouraged whereas previously I had controlled my liquid intake to reduce the risk of excessive leakage. I always knew that this was not good for the body but being out of control was frightening.

As women's anatomy is more complicated than men's, self–catheterisation is more difficult for women and the temptation to not persevere is easy to understand. For me, however, bladder distension resulting in kidney damage was a concern. I have had fewer problems since I have been self–catheterising and since reducing the amount of urine in the bladder irrigation has been less uncomfortable.

This technique is, for me, life changing and the inconvenience of self–catheterisation is minor compared to the constant worry about leakage. Without the support of my husband, Robin, taking on this new situation would have been much more difficult and both Robin and Kay Ikpeme, Continence Nurse Specialist at the NHS Worcester Health and Care Trust, have been there when I most needed their help.

Sonia Woolven

Dear Editor

I was given my colostomy in December 1984 just in time for Christmas. I used a bag for a short while until I was able to irrigate and have been doing so daily ever since. In all that time it has always taken over an hour to complete the process.

I was recently sent a Coloplast System. What a marvellous system. Whoever designed and manufactured this deserves a big thank you. I can now complete irrigating in under one hour because the water goes in straight away. The clever spinning wheel can be seen whizzing around so you can see it working.

Thank you
Richard Farrow

Editor's note: *In the last issue of* Tidings *we included a letter from a reader about ballooning. As a result of this we've had more letters on the subject. It's great to get feedback and any tips that will help others in a similar situation so please continue to write in.*

More information about self–catheterisation can be obtained from Urostomy Association: 01386 430140 www.urostomyassociation.co.uk

40th Wedding Anniversary Celebrations

I have been receiving the magazine now for many years and never thought that I would be writing an article for publication, that was always somebody else's job! Well now it's time to put pen to paper and let your readers know what I did for my wife and our 40th Wedding Anniversary last April. We travel and holiday to Turkey each year and celebrate our Anniversary each April, this year was no exception but being the 40th, made extra special by the guests attending.

This was our 31st visit to the Barut Hemera Hotel, Side in Turkey, after that amount of visits I guess you can work it out that we enjoy the place! I have had my colostomy now since January 1997 and have been fortunate to have travelled a fair bit, my attachment, I have never named it, has certainly been around but it is always Turkey that I return to, never having a problem, the weather, people and the hotel are just amazing, being well looked after certainly makes for a good time.

This year I planned for a celebration meal which was prepared and executed with the utmost culinary skill, a total of 24 guests were seated and the hotel pulled out all the stops to ensure a fantastic evening was had. Planning commenced in January with phone calls and texts to the hotel staff, all went well and on arrival we had a few days to iron out any problems. My wife Lyn had no idea at this stage, always wondering why I had to disappear every now and again, thankfully I play Table Tennis and could cover the absence.

We always travel with a group from Weymouth, most of which have been attending almost the same amount of years as us, we are good friends and look out for each other, they were informed of the surprise meal on arrival and were keen to attend and keep it a secret. I had one special friend who had not travelled for over 25 years, no passport and no idea!

He turned up the evening before and that's when my wife realized and was informed of why he was there! To cut to the chase, it was a great surprise, wonderful guests and amazing food and drink and to 'cap it all' my guests had a 'whip round' and presented us with their donation of which I informed them that I will forward to *Tidings.*

Attached are a couple of photos, our main man the 'Chéf' and a group table shot.

Oh, and of course, we are heading back next April!

Andy Clark

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Reversal surgery: one patient's story

Xenia Standbridge

Xenia Standbridge

As you will have gathered from Jennie Burch's article (see page 11) the decision to proceed with a reversal isn't necessarily as straight forward as you might think. But, with medical and surgical advances meaning that stoma surgery is increasingly seen as a temporary measure, it's a decision that more and more ostomates are likely to face. With this in mind, it was great to interview Xenia Standbridge about her reversal. I am sure that, like me, you will find the patient's perspective she offers informative and (for those of you about to have a reversal) the tips and advice she gives invaluable.

Xenia underwent an emergency Hartmann's procedure in early 2015. She was 46 years old at the time and, up until this point, had enjoyed good health throughout her life. On reflection, she thinks that this probably delayed her seeking help, as when she started to experience abdominal pain and then diarrhoea and vomiting, her early thoughts were that it was something that would pass. With the problems persisting, Xenia eventually went to her GP. Given Xenia's age, the initial thought was that her symptoms were linked to menopause. Over the next seven weeks she lost two stone in weight and was forced to cancel a skiing trip as her GP said she was unfit to travel. Matters came to a head on Christmas day. As a measure of the pain she was in, she could do nothing more than lay on the settee and watch her husband cook the Christmas dinner. In Xenia's words, he is a 'can't cook, won't cook man'. She managed to eat a small dinner, but within half an hour the pain had got so bad that following a call to 111, an ambulance was called. In hospital it was quickly established that she had a bad infection. Over the next 36 hours antibiotics were administered via an i/v drip and a CT scan revealed a growth (thought to be an abscess) on her left ovary. The initial plan was to use keyhole surgery to drain this and, if necessary, remove her ovary. But when it was discovered that the abscess had wrapped itself around the bowel and she had peritonitis, the surgeon performed the Hartmann's procedure. She was later advised that the bowel needed to rest and, if a reversal was possible, then this was likely to be in around a year's time.

Once home, Xenia was determined to wrestle back control of her life. Although she experienced the usual early accidents she tried not to let this get her down. In the year that she lived with a stoma, she went back to work, rekindled her social life, started back at the gym, went swimming, travelled by plane and even managed to go skiing. Her surgeon also confirmed that reversal surgery was possible. In the lead up to making the decision to go ahead, Xenia said that many of the considerations mentioned by Jennie Burch and in **Colostomy UK's** booklet *Stoma Reversal,* were not discussed with her. Although it isn't possible to say why, it shouldn't be concluded that this was an oversight on the part of the healthcare professionals involved. It is important to remember that the reasons people have stomas vary and so from a medical/surgical point of view the concerns around performing a reversal and the level of bowel function afterwards are patient specific. An issue that was discussed with Xenia however, was the fact that her reversal could not be performed using keyhole surgery. Hence, for her, the most difficult part of the decision to proceed was deciding whether she was physically and mentally ready to go through major surgery again.

Xenia's reversal was a success and her bowel movements started quickly afterwards. But it wasn't all plain sailing. In the days that immediately followed, she went through a process of mourning the loss of her stoma. This was not something that she had expected or been told to expect. She thinks that being upset in this way probably stemmed from a subconscious awareness that she had lost something that had saved her life. Xenia was also not prepared for waking up in the exact same ward that she had been in following her Hartmann's procedure. Unsurprisingly, this caused some emotional turmoil as she associated this particular hospital 'space' with being very seriously ill. Again, it is one of those things that you wouldn't even consider, but is certainly worth being ready for, should your reversal take place in the same hospital as your original stoma surgery. Finally, Xenia was very shocked by her surgical wound. Purposely left open, it was cleaned and packed each day, and left to heal gradually over the next six weeks. She wishes that she had been forewarned of this prior to surgery. Although it would not have stopped her going ahead, it would have lessened the shock afterwards.

CONTINUED ON PAGE 21, COLUMN 1

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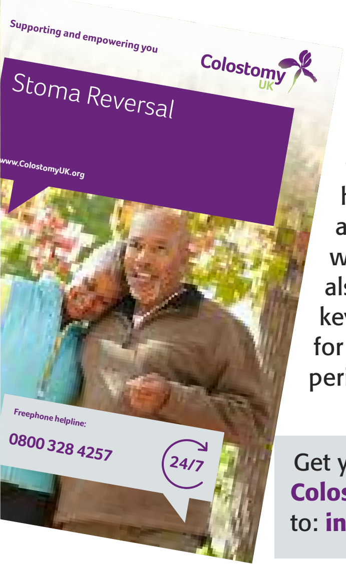
CONTINUED FROM PAGE 19, COLUMN 3

Xenia estimates that it took around a year to get back to what she considers 'full' fitness. Of course we all heal at different rates, but this was one thing that Xenia thought was crucial people took into account both when making the decision to go ahead with a reversal and also in deciding when was the best time to have it. She also mentioned to me a number of times that she felt it was vital not to rush returning to work afterwards. Her advice is to be upfront with your employer and also to be aware of putting yourself under too much pressure to return. Being self–employed, Xenia was able to manage her return. To begin with, she found that just half an hour a day answering e–mails was enough. Xenia also had two other key pieces of advice for the recovery period. Firstly, that people need to be prepared for some knockbacks. Her experience was not one of uninterrupted day–by–day progress. Xenia found friends and family were vital on off days; they reminded her that she had undergone major surgery. This helped her to keep things in perspective and focus on the destination of 'full health' rather than the road to reaching it. Secondly, Xenia feels that sometimes we are just a little too 'British' when it comes to our health. One thing she has learned is that not only should you ask for help but sometimes you need to be prepared to push and even pester until you get it.

I was very grateful to Xenia for taking the time to talk to me and I hope that anyone thinking about a reversal will have found some useful advice from reading about her experience. Please remember also, that we can arrange for you to speak to someone that has had a reversal, should you want further information. Our booklet on the topic is also free to download from our website. ■

Written by
Richard Biddle



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...walk away a bit taller!

Pamela Wickham

Like many people I wanted to make the most of my 60th year. As an active woman I had lots on the agenda, including a 'hot tub' birthday party in January, seeing Tom Jones in concert and having friends over from America. A mid-September trip to Northern Ireland for our eldest son's wedding was also part of the itinerary. But an item that wasn't there at the start, was to have a permanent colostomy. This came about through a set of extraordinary circumstances, involving a set of shelves, a tin of paint and a stool.

12 June 2017 was the fateful day, when I decided to give our utility room a much needed lick of paint. Being of diminutive stature, it wasn't long before I needed help reaching high bits. In particular the far corner, between the washing machine and the tumble dryer was a problem. Rather than get the step ladder (as I should have done…), I made what turned out to be a fatal mistake, and decided to stand on a stool. In the minutes that followed, my life changed forever. As I reached across to paint, my centre of gravity shifted and the stool toppled over onto a concrete floor. As I fell I imagined something horrible might happen, perhaps a broken hip or concussion, but never did I envisage the reality to come. I hit the floor with a thud and felt a searing pain in my lower abdomen. It was worse than I'd ever endured – including childbirth!

My screams brought my husband running. I'd wriggled my toes and satisfied myself that my hips were intact (I'm a retired theatre sister) but I knew I was going into shock. I also knew something was desperately wrong. When I rolled into the recovery position my husband announced I had a gash on my right buttock which looked like it would need stitches. As we waited for the ambulance I wondered what on earth could have caused this? Then I remembered the shelves I'd taken down and put on the floor 'out of the way' (brackets sticking up)…and realised I must have caught myself on one of them. At the time I dismissed this as unimportant compared to the pain in my abdomen.

A&E led to hospital admission. It was as I hobbled to the loo following a CT scan that the terrible truth started to unfold. It began, when my body decided to release some wind. This escaped from my newly acquired wound. I tried to tell myself this was impossible, but when brown fluid started to seep onto the bedsheets, I knew I must have perforated my bowel. When my husband brought in the shelf bracket the day after, the consultant was horrified. I had landed on 18cm of dirty, blunt–ended metal, which had penetrated my jeans, gone through my right buttock, perforated my pelvic floor muscle and ruptured the top of my rectum. And yet, initially, I didn't even know I'd scratched my skin, all I felt was the searing pain.

The week that followed included the indignity of having my backside ogled by hospital staff, not being able to have a bowel movement, feeling poorly, being pumped full of antibiotics and pain killers. The consultant then finally came up with a plan. On the Friday he announced that the only solution was a permanent colostomy, which he would do on Monday. I was dazed. By this point I had convinced myself that a colostomy would be the answer, but hadn't contemplated this as anything more than a temporary arrangement. And so, on 19 June, my Bertie was born!

CONTINUED ON PAGE 25, COLUMN 1


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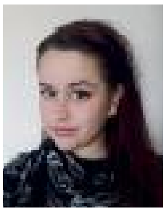

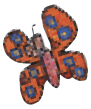

CONTINUED FROM PAGE 23, COLUMN 3

One week later I was home again. Now came the part of learning to live with Bertie. As you can imagine, I was concerned about what he might mean for my son's wedding, all the other things I had planned that year and whether I could cope with my American visitor. These worries were on top of those around supplies, how to order them, the mind boggling range of products available, the day–to–day management of my stoma and the implications for my 'normal' life. Luckily, I had an understanding pharmacist and patient stoma care nurse. With their help and my perseverance I found supplies that suited my way of life and, importantly, my skin.

Following surgery, my 2017 progressed more or less to plan. I saw Tom Jones 11 days post op and danced joyfully with my sister as we sang 'Delilah' at the top of our voices. My American friend came and we travelled around by train. I just made sure to have at least two bags, spray, wipes and disposal bags with me. I still do this now, keeping everything in my handbag in a ziplock bag which makes it quick and easy to access. I have subsequently found the travel bag that my stoma care nurse gave me is useful too. In places where there isn't much room, I hang it on the tap or toilet roll holder so supplies are at hand. My fear that the bag can be seen, smelt or heard has also lessened. I was determined to have an outfit of my choosing for the wedding rather than one to suit Bertie. Feeling pretty is important, but feeling feminine and dignified is non–negotiable! I found some specially made undergarments for ostomates that are like a camisole but really support and flatten the upper body, and make a bag almost impossible to detect, perfect for wearing underneath a wedding outfit. The wedding was wonderful, we sailed over to Belfast, and toured for a week afterwards.

As a new ostomate, I'm still learning. I've had some moments, but so far nothing that needed clean clothing! I have dealt with terrible cramps when I got a gastric bug. This taught me not to let the bag get too full or changing becomes challenging. I've learned to wear clothing that doesn't hinder Bertie. I've also found that bags don't always stick, but if I'm at home I gently warm the flange with the hairdryer and bingo it sticks! In November we went to the USA. I wasn't sure how airport security and a long haul flight would affect me, but it's my life not Bertie's so we went! It was all fine, I checked in advance where the nearest toilets were and ordered plenty of bags.

I'm not saying life with a stoma is easy, but I don't consider myself disabled. Like other ostomates I've had comments when using an accessible toilet. I just pass them off with the wonderful words of "not every disability is visible" and walk away a bit taller! This year we have a beach holiday booked with our young grandsons. Up to now I've been swimming in a pool, used a hot tub, sauna and steam room but not been in the sea, so this is Bertie's next test. Then we are going on a cruise round South America…a lot of supplies will be needed. If any readers have any tips for long stays away from home I'd be grateful to hear them. ■

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____

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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 you to get fit and healthy 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 being more active.

Team Colostomy UK Rugby League – Tackling the stoma stigma

In the last issue we wrote about our Team Colostomy UK Rugby League side and its imminent debut fixture against Medway Dragons Masters.

We're proud to say that the day went brilliantly and a team made up of people with a stoma, who have had a reversal, have a friend or family with a stoma, or who just wanted to play to help raise awareness, put on a great show.

Rather than just follow it up in this issue with the same boring old match report we thought we'd do something a little different and tell the story of the build up to the game and the aftermath through the words of those who took part in the day or have been inspired by the team's journey.

The launch

On 30 April we announced a partnership with Medway Dragons Rugby League Club which included a game between Team Colostomy UK and their Masters Team. The news was widely publicised in the Rugby League press and on social media. Here's an example of peoples comments:

> **Josh Pratt:** *"It great to see a Rugby League team, of all things, showing to everyone that it's [having a stoma] not something to be ashamed of!"*
>
> **Lynda Smith:** *"For the first time in 50 years I am proud to say I have an Ileostomy. You guys are making it acceptable!"*
>
> **Nicola Dames:** *"What **Colostomy UK** are doing is raising profile and awareness. High five to them, I think it's brilliant."*
>
> **John Flood:** *"Cannot wait to get involved with the brilliant awareness being made through this charity."*
>
> **Rocking2stomas:** *"This is so awesome. One day I would love to come and watch some matches. Fabulous idea."*
>
> **Local Buzz mags:** "Such amazing work going on at Colostomy UK."
>
> **Sue Drew:** *"Wonderful thing to do, a real positive message. I have a son with a stoma. It's knowing that life does carry on, maybe with some adjustments, but everything is possible."*
>
> **Colitis Cop:** "I think it's awesome!"

Building momentum

The media coverage we received following our announcement, and then at our kit launch at London Broncos gave us the confidence to approach a number of professional players with the idea of them becoming ambassadors for our project.

Oliver Holmes and Jy Hitchcox from Castleford Tigers, and Api Pewhairangi from the London Broncos all agreed to come on board and have been great at giving us further exposure, Oliver and Jy through their radio show on 'Proper Sport', and Api through social media. They were joined by three of our players

#ActiveOstomates

who we also invited to become ambassadors: John Flood, Kav Ellison, and Graham Wells.

> **Oliver Holmes:** *"I think what you're doing is amazing and we'll get behind you in every way we can,"*
>
> **Api Pewhairangi:** *"This is great! I'd love to help out and raise awareness in any way."*
>
> **London Broncos:** *"Wishing our friends at Team Colostomy UK all the best for their debut game against Medway Dragons on Saturday from all the players at London Broncos"*

Match day!

A very warm Saturday in July greeted the team as it took to the field in Gillingham to take on Medway Dragons Masters. The beauty of Masters Rugby League is that every game ends 0–0. The games are all about having fun and playing with a smile on your face.

Team Colostomy UK Rugby League exists to raise awareness and to give people the chance to prove that they can enjoy a contact sport like Rugby League after stoma surgery. I'll leave it up to you to decide whether the post game comments show if we have succeeded or not:

> **John Flood:** *"The day was awesome. Never thought I could play again with my bag. It was great to finally do it with this bunch of lads. Got my buzz back."*
>
> **Chris Caulfield:** *"Thanks for having me. Met so many great people too. Can't wait for the next one."*
>
> **Graham Wells:** *"Amazing Day…amazing people… can't wait for the next game."*
>
> **Jason Burbeck:** *"Great day, good bunch of lads and a great cause. Look forward to a return match soon."*
>
> **John Flood:** *"Today was the first time I've played rugby or any sport actually since my first op in September 2013. And damn I've missed it. Well done Team Colostomy UK was a huge success and a privilege to play on the same team as you all. Can't wait till next one,"*

CONTINUED ON PAGE 30, COLUMN 1

A Q & A with Julian Whitehouse on playing Darts with a stoma.

Name Julian 'The President' Whitehouse

Age 41

Home town Sutton Bridge Lincolnshire born in West Bromwich

How did you get the nickname Because of my surname

Darts used either Razor Edge 26g or Paul Hogan 24g

Walk on music A personal mix (made by myself) starting with the US national anthem into American Idiot (Green Day) finishing off with United States of Whatever (Liam Lynch)

Shirt design Colours inspired by Team Colostomy UK (Thank you) and Fremantle Dockers (AFL) with work logos (Emotive sound and light and Princess theatre Hunstanton), Maximum Darts (Local darts promoter) and Red Lips Design (Who made the shirt reality)

First started playing 2005 when I first moved down to Odiham in Hampshire

Hours practising Not as much as I like but do try to get as many league and competitions in as possible

Practice routine five minutes bulls eye to focus in then doubles round the board and 501 v computer at a higher level than myself

Biggest achievement reaching the regional finals for a national competition

Darts heroes BDO Paul 'Crocodile Dundee' Hogan and Scott 'The MOD' Baker. PDC Jamie 'Yozza' Hughes and Simon 'The Wizard' Whitlock

Frustrates you about darts Not being able to play at the ability I know I can following my operation (Its coming back slowly with hard work and dedication)

Advice to other players Relax and enjoy the game. (Even if your losing.)

Ambition I want to hold a charity game at Lakeside (home of British Darts) with a team of ostomates against a PCUK team. I'm sure we could pull this off

Likes outside of darts Avid fan of West Bromwich Albion and generally any sports. Music and photography

How did you get your Colostomy I was going through life as normal then around Christmas 2016 I found myself constantly wanting the toilet. In the February I went to the doctors who referred me to hospital. After my consultation I was diagnosed with rectal cancer in April 2017, by June I was booked in and had my Colostomy. In the September I started Chemo which finished April. I was getting told off by my Stoma nurse (Gill Skipper) for pushing myself so hard post surgery. Two weeks later I was playing darts again.

I am in a position where a reversal would probably only have a very low chance of success. I am proud of my progress and the things I've learned about having a Stoma.

#ActiveOstomates

CONTINUED FROM PAGE 29, COLUMN 2

> **Francesca Day:** *"Thank you Team Colostomy UK for inviting me to your inaugural game I loved every minute and it was great to meet the amazing and passionate people who made today possible."*
>
> **Matt Brown:** *"Great game representing Team Colostomy today. Cracking team on and off the pitch."*
>
> **Darren Feagan:** *"A great day of Rugby League. I can't wait for the next one."*

To build on the momentum of our first game two further matches have already been confirmed. The first, against South London Silverbacks, will have been played by the time you read this report. The second on 10 November will see the team travelling to West Yorkshire to face Keighley Cougars Open Minds.

For more info on our Rugby League project call Giovanni on: **0118 939 1537** or email: **Giovanni.Cinque@ColostomyUK.org**

Fancy a dip?

As part of Active Ostomates we work with support groups to provide free ostomate–only swimming sessions. We are looking for more groups to partner with throughout the UK to enable us to reach even more people.

Our latest sessions are taking place in the North East this October. On Saturday 13 October the venue is Sport Central at Northumbria University, on Saturday 20 October the venue is Gateshead Leisure Centre, and on Sunday 28 October we are at Woodhouse Close Leisure Complex in Bishop Auckland.

You do need to confirm your place in advance so if you would like to attend please call Giovanni on: **0118 939 1537** or email: **Giovanni.Cinque@ColostomyUK.org**

Chair Yoga

If you are involved in a support group and are based in Lancashire or Yorkshire we are now also able to offer our free chair yoga sessions to your group as well.

For further information please call Giovanni: **0118 939 1537** or email: **Giovanni.Cinque@ColostomyUK.org**

Revised and updated *Sport and Fitness after stoma surgery* booklet available

We have distributed over 6,000 copies of our *Active ostomates: sport and fitness after stoma surgery* booklet since its initial launch in 2016.

The newly revised and updated version is now available which includes new sections on modified sports and updated advice and links to numerous activities you can try.

To get hold of your copy either download it for free on our website, call us on: **0118 939 1537** or email: **info@ColostomyUK.org**

Why not also grab a copy of our *Healthy eating* booklet too? This gives useful guidance on how to achieve and maintain a healthy diet.

50K Challenge update

We continue to be inspired by the numbers of people signing up for our Challenge and the huge amount of kilometres that nearly 350 of you have cycled, walked, climbed, swam, ran, to name but a few activities, and also by the uplifting stories of how the challenge has encouraged you to be more active on a daily basis.

The challenge finishes on 31 October so there's still a bit of time for you to take part. To register and pick up your free t–shirt and pedometer just log on to **www.ColostomyUK.org**

We'll be running something similar next year so keep an eye on *Tidings* and the website for more information!

Colostomy UK
Purple Iris Stoma Care Award

The Colostomy UK Purple Iris Award recognises outstanding stoma care in community and clinical settings.

If your stoma care team has gone above and beyond in their care of you, a family member or a friend, then why not nominate them?

The 2017 recipients of the **Purple Iris Award** were the stoma care team at **King George Hospital in Essex.**

Nominations are now open for the **2019 award,** and we welcome nominations for stoma care teams who:

- **Deliver an exceptional level of care.**
- **Lead an excellent co–ordinated care package with other agencies and across a variety of health issues.**
- **Are innovative with their ideas to deliver outstanding patient support.**

A representative from the winning stoma care department will be invited to attend our **Open Day dinner in 2019** when an official presentation will be made by our President.

We look forward to receiving your nominations and to hearing about the amazing care and support being carried out by stoma care teams across the UK. Careful consideration will be given to all entries and we will feed back comments anonymously to all nominated teams in recognition of their invaluable efforts.

Purple Iris Stoma Care Award – Nomination Form

Your details

First Name: **Surname:**

Address:

Post code:

Telephone Number: **Email:**

Nomination details

Name of team/department:

Name of hospital/community setting:

Reasons for nomination: In two brief sentences, please describe what impact this team's support has had on your life or that of a family member (maximum 50 words) here:

Additional Information

On a separate sheet please explain why your stoma care team/department deserve this accolade (maximum 500 words). Please remember to head this up with your name and that of your nominee.

I give my permission for **Colostomy UK** to inform the stoma care team about this nomination including what has been written on this form.

Signed: **Name:** **Date:**

Please return this nomination form to: **Giovanni Cinque, Colostomy UK, Enterprise House,**
95 London Street, Reading, RG1 4QA by 30 April 2019.

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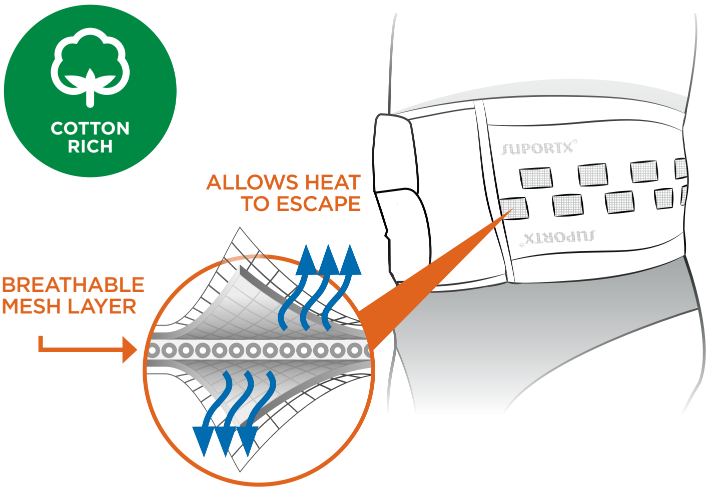

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Irrigation and you

Sarah Squire
Trustee and Co–Editor
E: Sarah.Squire@ColostomyUK.org

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

I am often asked why so few colostomates irrigate? Various statistics are thrown around. I'm told that more Americans do it, but I have American friends who say it's an English thing. I have struggled to find an up–to–date record of precise numbers. Two papers, published in 1999 and 2000 suggested just 1–2% of colostomates in the UK irrigate (O'Bichere et al., 2000; McCahon, 1999). I would hope this number has risen in the last decade – Colostomy UK have certainly tried to raise awareness and provide information to those wishing to try it.

We must remember though, some colostomates are unable to irrigate and others choose not to. Having a bag and letting it do its own thing works perfectly well for many and there shouldn't be pressure to try irrigation. If you are interested in trying, I am passionate that the information and support should be there. In the past I spoke to a lot of stoma nurses and most are enthusiastic while some are a little hesitant and lacked confidence. Colostomy UK produced two DVDs a few years ago, one as a training tool for nurses and one for patients. They are full of hints and tips and I recommend them to anyone who may be considering irrigation. I'm pleased to say that more and more nurses I speak to now are very keen to help patients irrigate as they see the benefits associated with the added control.

As a new ostomate over 11 years ago, I remember my stoma nurse mentioning this alternative method of managing my stoma. I briefly read the irrigation section in the literature I was sent home with, but it was all too much to take in when I felt my life had already been turned upside down with the arrival of the stoma. I was desperate for information though, to try and make sense of this 'thing' that I now had to look after, and took to researching all things stoma whilst lying on my bed with post–op fatigue. I searched everything from forums to scientific literature – my way perhaps, of dealing with things. I learnt all about looking after my stoma, the possible issues that may come up and how to deal with them. But I still skimmed the irrigation information as it looked messy, time consuming and, frankly, pretty scary.

I think many of us feel overwhelmed with information in the early days. There is so much to take in and just getting used to the stoma is a hurdle, but a couple of months in I began to wonder about this irrigation malarkey. My stoma was OK – I didn't (and still don't) like 'him' but life was getting back to normal. I was back at work and although changing the bag at work was not a problem I did like the idea of being more in control. I contacted my stoma nurse to arrange irrigation lessons and had three sessions with him at the hospital over the course of five days and yep, first time it was fiddly and I wished I had three pairs of hands, and yep there was mess although this was my fault for not sticking the sleeve on properly. But for the rest of the day, having an empty bag was amazing. It took a week or so to get into a routine and then I was off. I have never looked back since and would never choose not to irrigate now.

So what exactly is irrigation? How does it work and who can do it? These are questions I hear again and again from new colostomates who, like me, were possibly overwhelmed with literature in the early days and didn't know the option may be available.

Irrigation is a method of colostomy management which involves using specialist equipment to introduce warm water into the bowel via the stoma. The

CONTINUED ON PAGE 34, COLUMN 1

CONTINUED FROM PAGE 33, COLUMN 3

water causes muscular contractions (peristalsis) within the bowel which in turn cause expulsion of its contents. A long plastic sleeve is worn over the stoma and hangs into the loo so that the waste can be flushed away. The aim is to empty most of the colon which should result in no output between irrigation sessions. You will either sit on or next to the loo, although I do know some people who stand – I bought a folding deckchair in Argos just for irrigating and am very comfy! The kit includes a water bag which is hung at around shoulder height and is filled with warm water. Some people may prefer to use the B Braun electric pump rather than the gravity bag, which takes away the need for a hook to hang the water bag. Your stoma nurse will be able to advise you of the different options to help work out which is best for you. A tube comes from the bag or pump and has a soft rubber cone at the end that is gently inserted into the stoma. Remember you have no nerve endings in your stoma so you don't feel it. The bag or pump have a flow regulator so the water rate can be adjusted as you go, the idea being to slowly introduce enough warm water to encourage the bowel to contract and empty. Your stoma nurse will advise on water volume, but you will learn to feel when you are 'full'. The cone is then removed and you can relax for a few minutes – read a book, nip onto Facebook or crack that next Level on the Candy Crush game! During this time the bowel will contract and its contents empty down the sleeve and into the loo. Some people find it better to instil the water in two sessions but only using the amount of water that is recommended for them. Remember we are all different and your stoma nurse will help you find what suits you, but you will also adjust the technique over time to work well for you. You will learn to feel once all the water and waste has emptied, then you can clean up, pop on a cap, bag or maybe use a plug and that's it hopefully until the next session.

It does take time for adjustment to irrigation and there may be some 'breakthrough' during the first few weeks which should settle. The whole process takes around 45–60 minutes for most people. It may seem a large time commitment, but for me the peace of mind is well worth it – I use the time to catch up on emails, and I have even been known to write a *Tidings* article or two from my deckchair!

Some people only need to irrigate every 48 hours but as I keep saying, we are all different. Lots of things will affect the time we remain output free. Diet can have an influence – I know if I eat too many peas or drink red wine I will speed things up. I have a pretty fast transit time anyway so I am happy to irrigate each day and feel confident I will have an empty bag. Yes, I still use a bag – even after ten years I am too scared to use a cap. Very silly really but I like the reassurance that if any upset happened I am prepared.

If you like the idea of irrigating, the first step is to speak to your stoma nurse. Many people with a colostomy are able to irrigate, but there are some reasons which may mean it is not an option. Your stoma nurse will be able to discuss your individual situation and advise if irrigation is something you can try.

I still learn from others so please please continue to write in to me with your irrigation experiences and tips. I love to receive your emails. ■

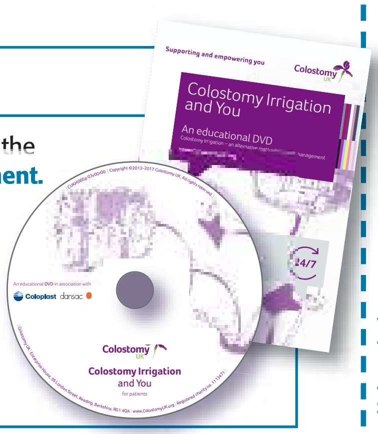
References

O'Bichere A, Sibbons P, Doré C, Green C and Phillips RKS (2000) Experimental study of faecal continence and colostomy irrigation, *British Journal Surgery;* 87 (7), 902–908.

McCahon S (1999) The pre and post operative nursing care for patients with a stoma, *British Journal of Nursing;* 14 (6), 310–318.

Colostomy Irrigation and You **DVD**

Order Form **Colostomy Irrigation** and You (Patients)



Colostomy Irrigation and You is an educational DVD aimed at patients, it has been produced by the **Colostomy UK** to raise awareness about ***colostomy Irrigation* as a method of bowel management.**
Note: Not all colostomates have the potential to irrigate. It is therefore essential in the first instance to consult your Surgeon/Stoma Care Nurse as they will advise as to your suitability.

To obtain your single copy of *Colostomy Irrigation and You* at the special price of £1.99 (incl postage and packing) simply fill in your details below and return it with your cheque made payable to the **Colostomy UK,** to:
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Please cut along the dotted line and return to the address on this form - thank you

"Well good for you!"

– from ostomate to volunteer

Dennis Pilmoor

I had been out of hospital for approximately two months and was managing my new colostomy reasonably well. I had been left to my own devices rather but with my pre–cut appliances I was becoming more adept and quicker at handling changes. Then it was a matter of returning to work. After a few weeks of phased return I began to have issues with soreness and pancaking. This dragged on and on and really got me down. I started to feel sorry for myself and thought like "why me?" and "what had I done to deserve this?".

Then one Saturday morning I looked to the internet for answers. I'd been told about **Colostomy UK** by my stoma nurse, she had told me of the good work they did for the rights of the ostomates. I rang **Colostomy UK,** not really expecting much, after all how could they help, they didn't even know me?

The phone was answered by a very well–spoken lady who turned out to be Sue Hatton, one of **Colostomy UK's** longstanding volunteers. When I said: "Hello my name is Dennis Pilmoor and I have a colostomy", she replied: "Well good for you". This took me by surprise and I asked why had she had said that, Sue then explained to me that it meant I was stronger than what ever had tried to kill me. I felt special, the advice I got that day changed my ostomy days.

Very soon after that conversation, I learnt that there was an open day planned in a hotel in Leeds organised by **Colostomy UK.** So my wife and I booked the hotel and travelled down to Leeds one Saturday morning. It was the best thing that I had done in a long time. We met some wonderful people including Sue Hatton and Jo McKenzie (who has worked at the charity longer than anyone else!). We heard an inspirational speech by Duncan Wells (another **Colostomy UK** volunteer) and even got to talk to the charity's president, consultant colorectal surgeon, Ian Daniels. I came out with three carrier bags of stoma product samples, from which I was able to pick products that suited me. I was starting to feel more confident and my outlook on my life was becoming brighter.

The main thing I took from that day was the concept of irrigation, I phoned my stoma nurse and asked about this and, to my surprise, was told no one in the northeast did this! How could this be true? At the open day I was told many of the UK's 120,000 ostomates did this, surely not all in the south? I persevered with the idea of irrigation and eventually I was cleared and taught how to do irrigation. From then on, no matter where I was in the world, I was able to irrigate. It gave me tremendous freedom.

I joined the Closed Facebook Group and became good friends with many of the members. I discovered on the group some of the most inspiring people you could ever meet. I had no idea there were people out there like that, people like me.

My three monthly meet came with my surgeon. By now I had acquired the dreaded parastomal hernia and to my surprise he mentioned reversal. We thought long and hard. My wife didn't want me to try, mainly because of the horror story of how I ended up with the colostomy in the first place. But me, being an engineer, thought if there is a chance, take it! So I decided to go for it.

After months of recovery, talking to people on the Facebook group, being cheered up by them and sad times as some left the group, some died, which shocked and saddened us all, I began to think I had something to give back. Likewise, although I was now 'reversed' I thought the experience of this was all valuable knowledge that could be shared too.

So, I went on a volunteer training course which was run by Sarah Squire and Duncan Wells. There were three others on that weekend in a hotel in Edinburgh. We learned about: **Colostomy UK**, various conditions, how to obtain supplies, how to advise patients who might be having difficulty getting what they needed from their GP and, of course, running through scenarios and training for work on the Helpline.

I'll never forget those days and every time I talk to someone that needs help with reversal issues I remember how I was helped by just that one line from Sue Hatton: "Well good for you". ■

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Have stoma, can travel

Jackie Dudley
Colostomate & Volunteer
E: Info@ColostomyUK.org

We often feature stories of people who have conquered their fears of travelling and are now confident globe trotters. But, we also realise that reaching this point can take time. In this article, Jackie Dudley, one of our long–standing volunteers, speaks about how by taking small steps to begin with, she gradually re–built her confidence following surgery.

At first having a stoma can take away your confidence. As I recovered I can remember wondering how I would manage a trip to the shops. Would my pouch fall off once I set foot outside the front door? What would I do if I needed a toilet and couldn't easily find one? What if I needed to change the pouch while I was out?

Over the following months I gained confidence and, of course, my pouch didn't come off in the few hours I was away from home. I began to relax and look forward to the car journeys and visits to friends. But the worry of having to change a pouch while out was a persistent concern. I got round this by taking short journeys to begin with and doing a recce of toilets that I might need. Finding out about the RADAR key and how this allowed me to use accessible toilets, relaxed me further. Slowly I felt my confidence returning. I also went everywhere with "emergency supplies" so that should the unexpected happen I could access a new pouch, wet wipes, adhesive remover and of course, the all–important RADAR key. I made sure I had a small spray deodorant so that I would leave the toilet clean and fresh. Another phobia I had to conquer.

I remained, however, very reluctant to go on holiday. Days out I could manage – even a coach trip provided the coach was not departing too early or returning too late! But it was while reading articles in *Tidings* that I began to realise that my refusal to consider a holiday was also trapping my husband and making him a prisoner of my concerns. Once I understood this, I began to consider how I could make a holiday possible, yet remain in control at the same time. Flying was too much to contemplate: I was concerned about managing the pouch "up there". But an idea started to form about a caravan holiday. This appealed because, amongst other things, I felt it would give me privacy in the bathroom. Importantly, I could choose how I disposed of used pouches without the worry of "someone knowing"!

I began researching caravan holidays and was amazed at the variety on offer; I was spoilt for choice. They also addressed my concerns regarding bathroom facilities and privacy. I found that you could even book a luxury caravan on a site that provided entertainment, a restaurant and a small shop for supplies. Once I started asking, I also found that friends and family were a good source of information too. It wasn't long before we took the plunge. Since then my husband and I have stayed in caravan sites all over the UK. Once we even hired a mobile caravan and toured Devon and Cornwall (a bit of advice – hire a small motorhome as the roads in Cornwall can be a little crazy!). I was completely relaxed as I was "in control" and my husband enjoyed the freedom of a holiday.

After experimenting with caravan holidays, and knowing I could cope, we tried a small hotel. No problem. If I was concerned about the disposal of a used pouch I just wrapped it up securely and carried it out to the nearest litter bin or dog bin. We have tried caravans, apartments and hotels now in beautiful locations, all giving me control and freedom.

Looking back, I see how important these steps were in regaining my confidence. Slowly I have used my knowledge of "how to cope" to take us abroad. The same rules applied. We began with short trips on aircraft or boats and stays in a villa or apartment where I had the privacy to carry out my regime. I also made sure to take plenty of supplies.

Next month we are flying to visit my friend in Florida. I have already requested travel information from **Colostomy UK** so that I can be confident about the long haul flight. I know that the freedom of travel is fantastic and following their advice I will be well prepared to enjoy the holiday of a lifetime.

I can remember reading in Tidings about the man that trekked around Nepal while I was unable to trek around Sainsbury's. My hope is that my story will encourage a new ostomate to follow in my footsteps. Do take that step. I regret not realising sooner how limited I was through my own fears of travelling and the problems I built up in my mind. I was also making it difficult for my family who wanted me to visit and share their holiday times. We now have a large map and place pins where we want to visit next. Maybe soon you will see a photo of us on our travels! ■


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“Take away yes, eat in no.”

Duncan Wells
Colostomate & Volunteer
E: Info@ColostomyUK.org

Having a stoma does nothing if not keep you on your toes. The default setting is for us to want to stay at home. Even now 12 years down the line, that is really my preferred option. “Dinner Party, Friday?” “No thanks”, “A Chinese or Indian?” “Take away yes, eat in no.”

I do go out of course but I need to prepare, to take the right kit, expect the unexpected, as in no disabled loo and to have options, which in some cases means knowing of a nearby disabled facility.

All ostomates and their stomas behave differently. To a large degree it depends on how much colon/large bowel you have. I have very little and behave very much like a baby – you put something in, and very shortly something comes out. And so I have to ‘prepare’. Right now I am about to go out on a racing yacht with a chap to take photos of the GPS chart plotter for my next book and so I have just had a cup of coffee this morning, no breakfast. That way I know that for the hour or so that we are out on the water I should be safe. I will have a pouch, flange and waste bag with me just in case. The same thing goes for flying. It pains me to have to ‘pass’ on the fabulous all day breakfast on offer in the terminal but I know I will have a reasonable chance of getting through a two hour flight if I have not eaten and the certain fact of needing a couple of changes if I have and aircraft lavatories are not easy places to effect any sort of change.

When it comes to security, especially flying, we will be expected to divest ourselves of, belts, keys, phones, watches, glasses, pens, shoes, and pass through the scanner practically nude. OK so not quite, but you get my gist. They may give you a light body search, a pat down, and when they reach my abdomen they will stiffen slightly and pause…they have found something…and I will tell them I have a colostomy. Ninety nine times out of a hundred they will say, “That’s fine” and I will carry on. Once the man at Düsseldorf security said: “Show me.” I could have gone to another room but I wasn’t bothered, so as discretely as I could, out there in public, I did. He looked and then felt the bag, mercifully not full – but then of course I hadn’t had the breakfast and was prepared for the security search and the flight – and then he let me go.

It’s no good feeling that this is an invasion of privacy or getting hot under the collar about it. In fact that is the quickest way to find yourself late for a flight, and it is, after all, in order to make us safe on our journey.

These people after all are just doing their job. Most are considerate, some are officious and you just have to bite your lip and answer their questions. **Colostomy UK** has a travel certificate in a number of languages. These are signed by your GP and declare that you have a stoma. It adds peace of mind if you prefer to have the information at hand.

While we are on planes, three things:

One, take all your supplies with you in the cabin luggage if you can, that way any ‘lost baggage’ will not have your stoma supplies in it. These days on short haul flights we are generally allowed to take our small case and put it in the overhead locker. Perhaps on long haul flights to somewhere that you will be staying for a month you may have to split the supplies but keep at least half with you. That way if the other half do get lost you will be covered for a while, during which you can either source supplies locally or get a UK Dispensing Appliance Contractor (DAC) to courier you an emergency supply. They might insist on a doctor’s prescription first but in an emergency I am pretty sure that a good DAC will help you out.

Two, quantity of supplies. Take more than you use at home. Your body will not be used to the food and may respond accordingly. It may be hot, you may go swimming and you may require more changes than at home. And take some drainable bags, even if you don’t usually use them. They may be handy in case of an upset stomach.

Three, yes the bag does increase in size very slightly as a result of pressurisation in the aircraft but this is nothing to be alarmed about, you may not even notice it. So long as the filter is working you shouldn’t have an issue so it’s always good to use a fresh bag for the flight. It has never caused me or anyone I know, any sort of problem.

And when abroad, especially in hot climates make sure you keep yourself hydrated. Take some Diaoralyte in case you ever need to replenish salts and minerals.

Watch out for ice in drinks and salads that have been washed with local water. Take advice from the tour reps/hotel staff.

My sail went well. It was only when we were back on the dock in the quiet of the cabin, going through a particularly neat piece of electronic navigation kit that my stoma made a small noise. Did my host notice? I’m not sure. It just goes to prove that you could stand in a field all day long and get not a squeak from your stoma but stand in a lift with others or go into a meeting and that is the time that your stoma announces its presence. It was ever thus. As I have always said: “A stoma will run your life but you mustn’t let it ruin your life.’

It will certainly keep you on your toes though. ■

Colostomy UK

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

Colostomy UK

Colostomy UK kit and merchandise

All profits raised from the following items help us to support and empower ostomates.. Order online at **www.ColostomyUK.org** or complete the order from below.

Team Colostomy UK Baseball cap

£8.99

Shipping £1.99

100% soft touch acrylic. Embroidered Team Colostomy UK logo on front. One size fits all.

Qty required: ....

Team Colostomy UK Beanie hat

£5.99

Shipping £1.99

100% cotton drill. Rip–strip size adjuster. Embroidered Team Colostomy UK logo on front and colostomyuk.org on back. One size fits all.

Qty required: ....

Colostomy UK Logo T–Shirt

£11.50

Shipping £2.99

Stand out from the crowd and show your support for **Colostomy UK** in our brand new logo T-Shirt. 100% heavy duty cotton.

Sizes available (inches):
Small (34"/36"), Medium (38"/40"), Large (42"/44"), XLarge (46"/48")

Qty required: Small ________ Medium ________
Large ________ XLarge ________

Team Colostomy UK RL Hooded sweatshirt

£31.99

Shipping £3.00

Team Colostomy UK Rugby League Hooded sweatshirt Acrylic/Cotton/Polyester mix. Features printed Team Colostomy UK and Masters Rugby League logos on front and #ActiveOstomates on back.

Qty required: Small ________ Medium ________
Large ________ XLarge ________

Anatomy aprons

£156.00

Shipping £4.95

A fantastic teaching tool for educating people about the various kinds of stomas. Aprons can help explain a variety of different surgical procedures including colostomy, loop colostomy, transverse colostomy, ileostomy, colectomy and hemicolectomy.

Qty required: ....

Team Colostomy UK Hooded sweatshirt

£34.99

Shipping £2.99

45% acrylic, 30% cotton, 15% polyester, 10% mixed fibres.

Embroidered Team Colostomy UK logo on left breast, and Printed logo on back.

Sizes available (inches):
Small (34"/36")
Medium (38"/40")
Large (42"/44")
XX Large (50"/52")

Qty required:
Small ....
Medium ....
Large ....
XX Large ....

Otto ostomy anatomy model

Standard £1,020.00

Advanced £1,260.00

Shipping £4.95

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

Standard Model

Stomas:
7/8" Diameter stoma
2" Diameter stoma
Loop with rod
Urostomy with 3" stents

Advanced Model
as standard model plus:

Stomas:
3" Diameter stoma
Loop without rod
Double barrel stoma
Oval stoma
Granuloma stoma
Necrotic stoma
Mushroom stoma
Prolapsed stoma
Ischemic stoma
Flush stoma
In–skin fold stoma
Parastomal hernia stoma
Mucocutaneous separation stoma
Recessed stoma

Additional parts included in both models: small intestine segment, ileostomy loop adaptor, colostomy loop adaptor, ileal conduit.

Qty required: ________ Qty required: ________

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

Please send me the above marked items. I enclose a cheque for £ ________ made payable to: **Colostomy UK.**

Title:

Name:

Address:

Postcode:

Tel:

Email:

Fullx3 01v02i00 CUK Merchandise - All | Date of Publication: October 2018 | Copyright ©2018 Colostomy UK | Registered charity no. 1113471

Opps a Daisy!

Marion Berekis

I'll never forget 22 May 2014… it was the day "Daisy" my stoma was created. The build up to this moment started late in 2013 when I noticed a change in my bowel habits (going to the loo more frequently and occasionally passing mucous and blood). My G.P. thought it might be diverticulitis but referred me for further tests as a precaution.

My first hospital appointment was late November 2013. The surgeon gave me a rectal examination and discovered a 'suspicious lump'. You could have knocked me down with a feather. At age 66 I was healthy and active. I had no pain, no weight loss and all the bowel screening tests I had done since retiring had come back clear. A cancer diagnosis never entered my head. Thankfully my friend Jean had accompanied me to the hospital (my husband Peter had Alzheimer's) and so I had someone to cry with. The surgeon explained he wanted a colonoscopy, CT scan and MRI done before Christmas. I agreed to attend any hospital to have these done quickly. Having been in nursing for 40 years I knew all the local hospitals. These tests confirmed the cancer diagnosis.

In January 2014 I started radiotherapy and chemotherapy to try and shrink the tumour before surgery. Side effects were dealt with almost before they appeared. Haemorrhoids and occasional lack of bowel control were unpleasant, but tiredness and other things were actually worse following treatment. Next it was the surgery. As a nurse I knew this would mean having a colostomy, but I didn't know whether it would be permanent. At this point I was too busy caring for my husband to worry too much about myself and had a positive attitude about my cancer. The surgery turned out to be extensive; an abdomino–perineal resection of colon rectum and anus. When I woke up I seemed to have tubes and drains everywhere, including an epidural for pain control. I still have detailed memories of my recovery, especially the three days I spent in the high dependency unit. My mind at this time was working overtime. Thankfully the hospital staff were excellent and the support I received from family and friends was tremendous too. As well as visiting me regularly, I had the comfort of knowing that Peter would be well looked after in my absence.

I was put on an accelerated recovery programme and the physiotherapists tried to get me up on my first post op day. My body told me otherwise. After sitting in a chair for five minutes

I was very sick, collapsed and had to be put back to bed and given blood transfusions. On my third day my children brought my husband to visit so he could try to understand where I was. He took one look at me and started crying. I had never seen him cry before. In the days that followed I slowly learned to cope with my stoma. I hated not being in control of my own bodily functions.

During my time in hospital I found I had too much time to think, but still struggled to visualise my future. I found a visit from the hospital chaplain very helpful. He chatted away, held my hand and prayed for me. After that my recovery seemed easier and quicker. On day eight, the surgeon visited and said that all the biopsies taken in theatre were clear of cancer. I remember asking him how he could explain that, and he said that although the radiotherapy and chemo had not shrunk the tumour they would have carried on working. I told him that I put it down to the "power of prayer" and he just gave me a funny look.

My daughter insisted on looking after me during my first week back home. After visiting her Dad who was in respite care she was involved in a car accident on her way to collect me from the hospital. Fortunately neither she nor my grandson were injured but oh dear – more worries I didn't need! Although she was a great help, she didn't want any involvement with my stoma. My G.P. was similar and said "If anyone can cope with a colostomy – you can". My two sisters then came to look after me the following week. We quickly established a routine of chatting and playing scrabble. They also made sure that I rested every afternoon. We also managed a trip to the garden centre for lunch. Unfortunately my stoma reacted violently, and although I had supplies with me I had to ditch my knickers in the bin and come home "commando style". We had a good laugh about that.

In the months that followed I felt I was coping. Despite episodes of pancaking and leaking, I kept a good diet, learnt by trial and error and started to restore some semblance of normality to my life. It was during this period that I christened my stoma 'Daisy'. This was because I kept saying "Oops a daisy" when she performed. I later realised that 'oops' is an anagram of poos! However, as we all come to learn with age, life has an uncanny knack of disrupting things. As I grew in strength my younger sister Fiona sadly died of cancer. I took this very badly and eventually needed counselling for 'survivor's guilt'. My husband's condition also started to deteriorate around this time and he died in June 2016 after a short illness. I was pleased to have been able to look after him for some 10 years but sad that, because of his condition, he never really understood anything about me and my stoma.

Since then life has continued to have its ups and downs. A number of blockages prompted me to try irrigation but I couldn't get on with it. I was so disappointed and am too scared to try again. My stoma nurse is great but has a massive case load and does not do home visits, and I really need someone there with me next time I pluck up the courage to try. In December 2016 I had a complete obstruction of my bowel, which required surgery in the end. Unfortunately, during this procedure the surgeon 'nicked' my left ureter which required repair by a urologist and the insertion of a stent. This meant more surgery accompanied by frequent urinary infections, antibiotics and, of course, stoma upsets as a result.

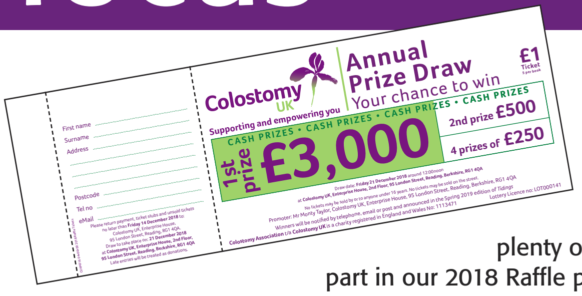
Despite all of this I remain positive and lead an active life. I love craft activities, doing exercises and church activities, and enjoying time with my four grandchildren. I have to watch my diet and still have the odd hiccup with Daisy. But we have been together now four years and are quite used to one another! I have had to adjust my lifestyle but I am still cancer free. My stoma saved my life, and I am very grateful that my faith, family and friends have seen me through the last four years. ■

Fundraising focus

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

Get involved!

Are you interested in fundraising for us? A successful event doesn't need to raise huge amounts of money. Rest assured, whether it be £5 or £500, **Colostomy UK** will put it to good use. 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 includes lots of hints and tips about organising an event, then call us on: **0118 939 1537** or email: **fundraising@ColostomyUK.org**



First name
Surname
Address
Postcode
Tel no
eMail
Please return payment, ticket stubs and unsold tickets no later than **Friday 14 December 2018** to: Colostomy UK, Enterprise House, 95 London Street, Reading, RG1 4QA.
Draw to take place on: **21 December 2018** at **Colostomy UK, Enterprise House, 2nd Floor, 95 London Street, Reading, Berkshire, RG1 4QA**
Late entries will be treated as donations.

Colostomy UK
Supporting and empowering you

Annual Prize Draw
Your chance to win

£1 Ticket
5 per book

CASH PRIZES • CASH PRIZES • CASH PRIZES • CASH PRIZES

1st prize £3,000
2nd prize £500
4 prizes of £250

Draw date: **Friday 21 December 2018** around 12:00noon at **Colostomy UK, Enterprise House, 2nd Floor, 95 London Street, Reading, Berkshire, RG1 4QA**
No tickets may be sold by or to anyone under 16 years. No tickets may be sold on the street.
Promoter: Mr Monty Taylor, Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA
Winners will be notified by telephone, email or post and announced in the Spring 2019 edition of *Tidings*
Lottery Licence no: LOT000141
Colostomy Association t/a **Colostomy UK** is a charity registered in England and Wales No: 1113471

2018 Raffle

There's still plenty of time to take part in our 2018 Raffle prize draw. Tickets were enclosed in the spring issue of *Tidings.* If you've not returned yours yet don't worry as they can be sent back anytime up until 14 December 2018. If you run out, then further books can be obtained by emailing **info@ColostomyUK.org** or calling **0118 939 1537.**

This year the first prize is £3,000. The second prize is £500 and there are four third prizes of £250

The draw will take place on 21 December 2018. Winners will be notified as soon as possible afterwards. All proceeds go towards supporting our core services, projects and campaigns, so by purchasing a ticket you are helping to make a difference.

giftaid it giftaid it giftaid it

If this edition of *Tidings* has inspired you to make a donation to **Colostomy UK,** then you may be interested to know how just a simple tick in a box can add 25% to your donation. And, the great news is, it won't cost you a penny more either!

What is Gift Aid?

Gift Aid is a simple way to increase the value of your donation to **Colostomy UK.** If you pay tax in the UK, we can reclaim the basic rate tax (25%) on your gift. So, if you donate £15, it is worth £18.75 to us.

Here's our simple guide to making your donation go further.

Do I qualify for Gift Aid?

Your donations will qualify as long as they're not more than four times what you have paid in tax in that tax year (6 April to 5 April). The tax could have been paid on income or capital gains. Visit **https://www.gov.uk/donating-to-charity/gift-aid** to find out more.

How do I sign up to Gift Aid?

The process is simple. All you need to do is to tick the Gift Aid declaration when you compete the donation form (see page 47). If you prefer to donate online via our website, then you will see the same declaration. Again, all you do is to tick it. You can also donate by telephone. If you donate this way, then just tell us that you want to make a Gift Aid donation and we will do the rest!

What does the Gift Aid declaration commit me to?

Nothing! It just ensures that if you choose to donate to **Colostomy UK,** we can claim an extra 25% back from the UK Government.

What is a Gift Aid declaration?

A Gift Aid declaration is a statement by an individual taxpayer that they would like a charity to receive the tax paid on their donation back from the UK Government.

How long does the declaration last for?

To simplify matters for both you and **Colostomy UK,** the declaration wording normally covers present, future and past donations. We can back–claim payments made over the past four years and we will continue to claim until you tell us otherwise.

What do I do if my tax status changes or I want to cancel my declaration?

To let us know if you stop paying tax or wish to cancel your declaration, please use the enquiry form on our website, write us a letter, send an email to **info@ColostomyUK.org** or call us on **0118 939 1537.**

Will making a Gift Aid declaration really make that much difference?

You may think that getting an extra £5 from a £20 donation is hardly worth the bother. But let us assure you it is. Imagine if a thousand people who were eligible didn't sign the Gift Aid declaration…**Colostomy UK** would be missing out on an extra £5,000, which we could put to good use helping and empowering ostomates across the country.

giftaid it

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.

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.

Unity Lottery

It's now been over two 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 5 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 36 or online by visiting **www.unitylottery.co.uk** Just remember to link to **Colostomy UK!**

Run in the sun!

The warm weather this summer certainly encouraged some of you to get out and be active. As well as all our army of 50K Challenge participants we've also had a number of other people take on other challenges for **Colostomy UK,** we're pleased to feature a couple of them here:

Back in June, staff from Bakers Waste Services took part in a charity 5K Inflatable Obstacle Course at Leicester Racecourse.

Paul Baker, Lewis Baker, Ben Baker, Jamie Lee, Simon Brown, Marek Pracowity and Michael Harvey competed to raise over £170 in support of a colleague of theirs who has a stoma.

Iris Lovell ran the Belfast Marathon and raised over £1,000. She chose to run for **Colostomy UK** as "you provided very valuable support to a colleague after surgery".

News from local support groups

Bishop Auckland stoma support group 35th anniversary reunion – Thursday 17 May 2018

L–R: Honorary member and Consultant Colo–Rectal Surgeon (Retired) – Mr John Stephen "A very fine surgeon", Audrey Quinn, Sandra Parrett, Dennis and Margaret.

Maureen Davison our organiser, co–founder, extremely hard working and well loved.

All of us with Sister Barbara (retired), our co–founder with Betty Towns – much loved and hard working with Betty Walker standing beside her

We regularly see 25 to 30 members every month, and have a guest speaker from one of the many stoma care companies, followed by refreshments, and then general informal discussion between ourselves on any subject that any member wishes to speak about. There are no membership fees, and all ostomates, relatives and their friends are welcome

Our Founders – Stoma Clinical Nurse Specialist Sister (Retired) Barbara Mattinson (née Hodgson) and Mrs Betty Towns – together with Mrs Maureen Davison – joined with our Honorary Member and Colorectal Surgeon – (Retired) – Mr John Stephen – and members, relatives and friends to celebrate 35 years of support, friendship, various activities, overnight trips, days out and meals – for an Anniversary Reunion Lunch on Thursday 17 May 2018.

Our adage "A trouble shared is a trouble halved" – has been true to its tenet and many stoma patients and their loved ones have attended our fortnightly meetings for 35 years.

Bishop Auckland Stoma Care Group has helped hundreds of stoma patients young and old.

All stoma patients have an inherent understanding of the trauma which is suffered by a stoma patient – from the illness necessitating the surgery through treatment to surgery – learning how it feels to have a part of one's anatomy outside your body and how it affects body image, confidence, self–esteem, and life's activities which we take for granted – until we have such serious surgery.

Bishop Auckland Stoma Support Group has been responsible for helping stoma patients to re–discover themselves, gain confidence and enjoy open, honest and frank conversations – meet various Stoma Supply Company's representatives, sample various products, and discuss issues in a safe, non–threatening and non–judgemental environment.

We enjoy a supportive relationship with our Stoma Nurses who demonstrate care and interest in all their patients new or established. Laughter is always a main feature of our get–togethers and we welcome any new patient with open arms.

I should also like to mention that over the years we have been the recipients of various awards including the Durham County Council Chairman's Medal for Outstanding Service to the Community; The Bishop Auckland and Shildon AAP Certificate for Outstanding Community Service and DDES CCG Award for Patient – Stoma Nurses/CCG Engagement demonstrating what can be achieved when patients engage with Clinical Staff in a meaningful way.

Over the years we have lost many dear members but we refuse to be too sad and continue to embrace one another and share the contents of one another's hearts.

"Viva Bishop Auckland Stoma Care Group!!!!!!"

Location: St. Mary's Church Hall, Vart Road, Woodhouse Close Estate, Bishop Auckland, County Durham DL14 6PQ.

Contact: Maureen Davison – phone: 01388 818 267. Or e-mail: trebornosivad@tiscali.co.uk for more information and dates of our meetings.

Sandra Parrett

FUNDRAISING
Colostomy UK

Make a donation

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

My Details: Title: Forename: Surname:

Home address:

Postcode:

Telephone (home): Mobile:

Email:

Date of Birth: Month and year of operation:

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

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

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

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

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

I would like to make a donation of:

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

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

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

Card number (Maestro only)

Expiry date /

Security code

(Maestro only) Start date /

(Maestro only) Issue No.

Signed

Date D D M M Y Y

giftaid it Thank you for your gift

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

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

Signature: Date: / / 2018

I would like to make a regular donation – Instruction to your Bank/Building Society to pay by Banker's Standing Order:

To the Manager: (Bank or Building Society)

Bank Address: Postcode:

Name(s) of Account holder(s):

Account number: Sort code:

I would like to make a regular donation* of ☐ £20 ☐ £30 or other amount (please state) £

☐ monthly ☐ quarterly ☐ annually starting on the ☐ 1st ☐ 15th ☐ 25th of month: year:

thereafter until further notice. (Please cancel any previous standing order in favour of this beneficiary).

*Please allow one month's notice to ensure donation processes through banking system and state your donation amount in words:

Please pay: NatWest Bank, Market Place, Reading, Berkshire, RG1 2EP

Account name: **C.A. Ltd** Account No: **88781909** Sort code: **60-17-21**

Name: (IN CAPITALS)

Signature: Date: / / 2018

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

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

Registered Charity No: 1113471

Registered with FUNDRAISING REGULATOR

News from local support groups

Hampshire Ostomates Support Group

This support group was founded by Nicki Beare who had a permanent ileostomy 8 years ago. She quickly realised the pressure the Stoma nurses were under and felt there was also a lack of support in the area that she lives in.

Location: Andover War Memorial hospital.

Facebook: Search for Hampshire Ostomates Support Group, offering support and advice or just a general natter amongst patients. Emma Cutler is a member of the group who is one of Winchester hospitals Stoma nurses. Emma is always on hand if patients need her.

Please contact Nicki for more information email: Nichola0405@yahoo.co.uk phone: 07771 558 458.

All are welcome, including friends, family and carers.

Nicki is also and is looking to start a second group in Winchester very soon, if you are interested please do contact her.

Nicki Beare

Ashford Stoma Support group

L–R: Ann Mc Gregor – Chair (Patient) of the Ashford Support Group; Dr Derek Mitchell – Patient Advocate; Lisa Hanson – Stoma Support Nurse; Mr Ramalingam – Consultant Colorectal Surgeon; Carol Hobbs – Chair (Patient) of the Ashford Support Group; Leo Gribbon – Senior Territory Manager Dansac; Jackie Hawes Patient Coordinator of the WHH stoma dept.

Contact Carole Hobbs 01303 814 014
Margaret Webb 01233 628 807

Last Thursday our Monthly Stoma Support group took place at Tesco Community room at Tesco Store Crooksfoot.

This support group has been running for several years and it is run by our patients (Ostomates). Mr Ramalingam Consultant Surgeon came to do a talk about living with a stoma, the history of stoma procedures. and the complications that can arise."

Contact: Carole Hobbs: 01303 814 014 or Margaret Webb: 01233 628 807 for more information on the support group.

Lisa Hanson
Stoma Support Nurse

Norfolk Ostomates Support Group

L–R: Sue Smoothy, Barbara Harris, Lindsay King and Jane Keeton.

This was the first meeting of Norfolk Ostomates Facebook group at a lovely pub by the river in Norwich where we had a lovely meal, drink and eye opening revelations of our respective journeys to becoming Ostomates.

It was so enjoyable for all of us to be able to chat freely and for our stomas to noisily pass wind without embarrassment but we decided not to all change bags at the same time for fear that the management might need to evacuate the building!

Thank you so much to Sue Smoothy, Lindsay King and Jane Keeton for their excellent company.

Any Ostomates in Norfolk please look up our Facebook group and join us, the more the merrier.

Contact: Barbara Harris, phone: 01603 417046 or 07789 581312. E-mail: bmharris@mail.com for more information.

Barbara Harris

Shropshire B.O.T.s (Bums on Tums)

Each year we celebrate the "B.O.T.s" birthday with a lunch or tea party, and this year (our 7th) we went to the lovely Orangery restaurant at the Derwen College in Gobowen. The college is a training centre for people with special needs, and has a large garden centre and farm shop which are open to the public, as well as a coffee shop and the Orangery.

We decided that we would indulge in their fantastic afternoon tea. 41 members of the Group met at 3pm to enjoy the scones, cream and jam, sandwiches, and the most scrumptious array of cakes. (If you live near here, you must try it!)

After the tea, we all went and sat outside and talked and talked for about an hour before drifting off home – replete. This is one birthday tea none of us will forget in a hurry.

We are all looking forward now to our Open Day in Oswestry on 11 October. For details see Open Days in this magazine.

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.

SHROPSHIRE B.O.T.s (BUMS ON TUMS) STOMA OPEN DAY
Memorial Hall, Smithfield Street,
Oswestry, SY11 2EG
11October 2018 10:30am–3:00pm
Irene Constable 01691 238357 Email:
ireneconstable@phonecoop.coop

CliniMed Event
Warwickshire Golf & Country Club,
Spa Room, Leek Wootton, Warwick,
Warwickshire, CV35 7QT
Tuesday 16 October 2018 10:00am

CliniMed Event
Birchwood Park Golf & Country Club,
Birchwood Road, Wilmington,
Kent, DA2 7HJ
Wednesday 17 October 2018 11:00am

Musgrove Park Hospital Stoma Care Open Day
Somerset County Cricket Club
(Priory Bridge Road Entrance),
Taunton, Somerset
Tuesday 23 October 2018
10:00am–2:30pm

CliniMed Event
Ballroom – Drayton Court Hotel,
2 The Avenue, Ealing, London, W13 8PH
Tuesday 30 October 2018 1:00pm

York Stoma Wellbeing Day
Double Tree by Hilton Hotel,
Monk Bar, York, YO31 7JA
Saturday 24 November 2018
10:00am–2:00pm

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 01202 674336
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

Beating Bowel Cancer UK
www.beatingbowelcancer.org
Telephone 020 8973 0000

Bowel Cancer UK
www.bowelcanceruk.org.uk
Telephone 020 7940 1760
e–mail admin@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

England

Bedfordshire
Saturday Social Club
Karen Richards: 01234 792 278

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

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

Buckinghamshire
High Wycombe Stoma Support Group
Jan Peacock telephone 0800 318 965, e-mail peaky461@gmail.com
Milton Keynes Stoma Support Group (MKSSG)
Morag Harvey (Secretary)
mkssg.sec@gmail.com 01908 567 091
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
Jane Shaw: 01925 662 103

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

Co. Durham
Bishop Auckland Stoma Care Group
Mrs Maureen Davison tel: 01388 818 267 email: treornosivad@tiscali.co.uk
Darlington Support Group
Sister Jacqui Atkinson: 01325 743 005
Durham Stoma Support Group
Sister Maxine Santana 0191 333 2184

Cornwall
Cornwall & Plymouth Bowel Cancer Support Group
The Chairperson: 01726 828 419 or The Secretary: 01872 241 145, cbcsginfo@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 015395 33279
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

Devon
Devon IA
Martin Hornby: 01458 251 095 or email: devon@iasupport.org
Mid Devon Ostomy Support Group
Janice - janice234ford@gmail.com
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

Gloucestershire

Vale Stoma Support Group
jfn.dursley@gmail.com
or text 07941 827 393

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

Hertfordshire

Colonise
Anastasia 01727 760 981

Ostofriends Support Group
Peter Lannen ostofriends@gmail.com
07501137 511

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

Isle of Man

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

Stoma Support Group
Carole Cringle stoma nurse: 01624 650 212

Isle of Wight

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

Semi-Colon Club
Tony Crowson on 01983 559 326 or
Cancer Clinical Nurse 01983 534 180

Kent

Ashford Stoma Support Group
Carole Hobbs: 01303 814 014 or
Margaret Webb 01233 628 807

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

Dartford Ostomy Group Support (DOGS)
Tracey, John or Sue: 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, Helen or John
on 07948 974 350

M.O.G.S (Medway Ostomy Group Support)
Helen Or Tracey: 07773 605 534

Maidstone Stoma Support Group
Judy/Kirsty: 01622 224 305

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

Sheppey Ostomy Group Support (SOGS)
Shelley 07714 734 194
E-mail: sogs-uk@hotmail.com

SWANS Stoma Support Group
Heather - 07711 445 312

Thanet Stoma Buddies Support Group
Kathy 01843 291 825

Lancashire

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

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

Leicestershire

Kirby Ostomy Support Group. Colostomy, Ileostomy and Urostomy in Leicestershire
Janet Cooper: 0116 239 2844 /
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, scyana@tiscali.co.uk

Homerton Hospital Bowel & Stoma Support Group
Angela Davy: 020 8510 5318
or 020 8510 7599

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

I.C.U.P.S ,
Sue: 07742 237 013

St Helens Cancer Support Group
01744 21831, Denys Floyd- 01744 884097 or email:
contact@sthelenscancersupportgroup.org

Middlesex

Inside Out
Sarah Varma: 020 8235 4110
Bob (chairman): 020 8428 4242

Norfolk

James Pagett Ostomy Support Group (Afternoon Meeting)
Vicki Blackwell on 01493 663 363

James Pagett Ostomy Support Group (Evening Meeting)
Sandra Hutchings: 0150 258 5955

Kings Lynn Ostomy Friendship Support Group
For more info please call 01553 775 698 / 01553 674 962 / 01553 768 271

STARS (SToma And Reconstructive Surgery social support group)
Sylvia Hughes 01263 733 448
sylvia.ruth.hughes@gmail.com

Norfolk Ostomates Support Group (on Facebook too)
Barbara Harris 01603 417 046
07789 581 312

Northamptonshire

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

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull: 07714 479 320

Hexham Ostomy Group
Judith on 07967 927 286

Northumberland Cancer Support
members@northumberlandcancersupportgroup.co.uk

Nottinghamshire

North Notts Stoma Support Group
Tore and Nicky Norman: 01773 715 460

Nottingham QMC Stoma Support Group
Rosemary Brierley: 0115 982 6691

Nottingham Stoma Support
Jenny or Kate: 0115 962 7736
Mrs B Heath: 0115 966 3073

Shropshire

B.O.T.S. (Bums on Tums)
Irene Constable on 0169 123 8357

Staffordshire

Outlook
Moira Hammond 07788 402 195

Suffolk

East Suffolk Ostomy Group
Marion Fisher: 01473 311 204

L.O.G.S (Lowestoft Ostomy Group Social)
Mandy O'Shea: 07899 913 617 or
Bruce Pollard: brucepollard@me.com

West Suffolk & District Stoma Group
Jessica Pitt stoma nurse: 01638 515 525

Surrey

Epsom and District Stoma Support Group
Lindsay, Trevor or Sheena: 01372 735 925

Normandy Colostomy Support Group
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
John Burchell 0191 265 1047

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 0797 4657146 email: midyorks.bottomsup@gmail.com

Dewsbury & District Ostomy
Janet Edmond: 01924 512 041 or 01924 512 072

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

Colostomy UK Volunteers Northern Ireland
Chris Wright: 07720 717 771

Belfast City Hospital Stoma Nurses
Audrey Steele, Karen Boyd, Kirsty Niblock, Annette Lambert, Emma Dunn tel 028 9504 5941

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

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

GOSH (West Lothian)
Scott Pattison: 07502 163 644

Bring Your Own Bag Stoma Support Group
Western General Stoma Team 0131 537 1000

Wales

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 237847
or Julian Boswell 01554 772 877

Conwy

North Wales Ostomy Support Group
Hazel - 07976 817 246
or Lesley - 07828 837 325

Flintshire

Bag For Life Stoma Support Group In.It.Together
Faye Jones 07852 750 772

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
Chairperson on 01685 877 144

Pembrokeshire

PSA (Pembrokeshire Stoma Association)
Roy Whitfield 01437 760 701

Powys

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

Rhondda Cynon Taf

Royal Glamorgan Stoma Care Support Group
Domenica Lear 01443 443 053

Swansea

Swansea Ostomy Self Help Group
Glynis Jenkins: 01792 418 245

Republic Of Ireland

County Mayo

Mayo Stoma Support
Marion Martyn: 0949 021 733

Dublin

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

No one should face stoma surgery alone

Colostomy UK

Make sure they don’t – donate now

Text **CASS01** and amount to **70070**

online at **ColostomyUK.org**

0118 939 1537