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Tidings



**My two stomas
Ping & Pong...**

page 24



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Dear readers



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Sitting down to write this I can't believe it's the autumn already. I hope plenty of you were able to get away this summer. I managed a couple of weeks in Sicily. Being a history buff, this was a dream destination. The sunny weather and good food was just the icing on the cake...honest!

With the exception of 'Dear nurse' this edition of *Tidings* has all the regular features. Our real lives' stories cover returning to work after stoma surgery, the impact of stoma surgery on mental health, and one man's determination to carry on enjoying an active lifestyle despite bowel cancer necessitating a colostomy. We also have a trip down memory lane for our more seasoned ostomates, with a story about having a stoma in 1968. This one has wider relevance too, as the author talks about having a baby after her stoma was formed. The Bowel Disease Research Foundation (BDRF) have contributed an interesting article outlining the research they do. As you will see, there is the potential here for you to shape the content of their future submissions. If you have any suggestions in this regard, then please drop me a letter or e-mail.

I know from chatting to people at our Big Open Day in June, that 'Dear nurse' is missed by many readers, so I thought it would be helpful if I explained why it is absent again. The reason is very simple: we haven't received a single question for our nurse since the middle of last year. I'm convinced that this is partly down to the growing popularity of online groups and forums. My feelings about seeking advice in this way are mixed. On the one hand, people can pose questions and get very quick responses (much quicker than waiting for an answer in *Tidings*). But on the other hand, I have concerns about some of the advice given, particularly when those giving it are lay people encroaching on medical ground. My view (and that of **Colostomy UK**) is that medical queries should always be directed to a healthcare professional and, if the matter is urgent, then people should call their stoma care nurse and/or GP, rather than turning to their computer for an answer. You'll hopefully be pleased to know that we haven't given up on the Dear nurse feature, but we do need your assistance to run it. So please: write, e-mail, or even telephone us, with your questions. We have also decided to broaden things out, in the hope that this will help. Hence, we are now looking for stoma-related questions to direct not just to stoma care nurses but surgeons and dietitians as well.

I'm going to sign off by saying something about the new NHS formularies and stoma prescribing services, which I know are causing concern (see letters page 31). In brief: Clinical Commissioning Groups (CCGs) across the country have started to change the way in which repeat prescriptions for stoma products are issued and delivered. The stated aims are to make sure that the needs of patients are reviewed regularly so that they receive the right products while, at the same time, reducing waste and costs (arising from patients ordering/being ordered either the wrong products or the wrong amounts of products). **Colostomy UK** is currently gathering information as a precursor to deciding what our role should be as a charity that supports and advocates on behalf of ostomates. Unsurprisingly, the emerging picture is complex, with seemingly little consistency in terms of how CCGs across the country are implementing changes. In summary, we are on the case and will keep you updated.*

Tidings Magazine:

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*Shortly before going to print we were consulted by Liverpool CCG about the changes they plan to make. We see this as a positive development.



Richard

Richard Biddle
Editor,
Writer & Researcher

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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

Stoma helpline for:

Emotional support, experience based advice and guidance from a volunteer.
0800 328 4257

24 hours a day and completely free.

Adminline for:

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

0118 939 1537

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

info@ColostomyUK.org

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

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Donating to Colostomy UK

An annual donation of £20 (or whatever you can afford) allows us to produce *Tidings* and to continue our vital work, supporting, and empowering ostomates – see page 42 for donation form.

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



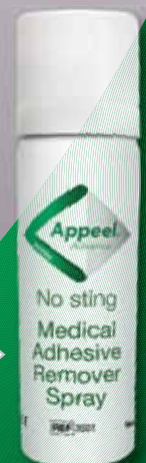
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Colostomy UK: news

Out and about...



At the end of June, Richard and Giovanni attended the East of England NHS Collaborative Procurement Hub StoMap conference in Newmarket. The aim of the StoMap project is to understand how stoma products are selected, prescribed and dispensed, and how services are commissioned in the East of England. The hope is that this will ultimately reduce variation in product availability, introduce best practices, ensure that patients are central to decision making and lead to sustainable services with transparency in spend. We were pleased to be able to attend. See Dear readers (page 3) for more about NHS formularies.



Libby and Giovanni attended the Association of Coloproctology of Great Britain & Ireland's (ACGBI) annual conference in Dublin in July. Each year this three-day event brings together colorectal surgeons, nurses, charities and patient liaison groups. It was great being able to raise awareness about Colostomy UK's work with those who attended. We were also able to catch up with our friends at Crohn's & Colitis, The IA and the newly formed Ostomy Association of Ireland.



For those of you that don't know, Purple Wings is a charity who, like us, are dedicated to supporting ostomates. They held their annual conference and ball in August and Libby was invited to go along. Nicola Ridler (soon to be **Colostomy UK** volunteer) joined her too. It was a friendly event with lots of inspirational speakers and an excellent opportunity for our two charities to come together. Thanks to everyone at Purple Wings for the invite!

Romanian Ostomy Patients Support Foundation



Become a trustee of the Romanian Ostomy Patients Support Foundation and

share your experience.

In 1996, the Ileostomy & Internal Pouch Support Group together with the British Colostomy Association and the Urostomy Association worked on a collaborative project to help ostomy patients in Romania. In 2000, this ostomy group formed the Romanian Ostomy Patients Support Foundation (ROPSF) and its work continues, in order to improve the life of those patients who undergo major abdominal surgery leading to the formation of a stoma. Through ROPSF help is also given in training carers, as well as nurses and those from the medical profession.

Very many of the patients have a colostomy and currently ROPSF is looking for one or two new trustees with a colostomy to augment the valued work that is being undertaken by the present trustees. Be assured that this is a most interesting and rewarding part-time role joining a dedicated group of people focussed on improving the wellbeing of Romanian ostomy patients young and old.

For more information about the charity please view the website: www.ropsf.co.uk or speak with the Project Director, Bob Bailey on: **01892 663 112**



As we reported in the last edition, **Colostomy UK** have recently teamed up with Target Ovarian Cancer. We are pleased to announce that the booklet we have co-authored is now in print. Based on the latest evidence and full of insights from women with ovarian cancer who also have stomas, it addresses the common concerns people have pre and post-surgery. Copies can be downloaded from our website (www.ColostomyUK.org) or call our admin line: **0118 939 1537** and we will send you one in the post.

Stoma-friendly society update

We have had some more great news:

- ◆ Theatre Royal Nottingham and Nottingham Concert Hall now have stoma friendly accessible toilets. If you look at the letters page (page 31), you'll see that this has already been noticed by one of our readers!
- ◆ Meadowhall Shopping Centre, Sheffield (the largest shopping centre in Yorkshire), are completing upgrades to their accessible toilets (18 in total) and so should soon be stoma friendly too.
- ◆ We are continuing to work with airports across the UK and were recently invited by Gatwick to sit on their accessibility forum.

Back to work and life after colostomy

Lesley Denton



The countdown to my retirement has started and I can't wait. Having worked all my life I reckon I'm due a rest, particularly after the last few years.

These included a diagnosis of bowel cancer, stoma surgery, chemotherapy and then the ordeal of returning to work. I'm sure that the latter is something that many readers will have faced, or are about to face, regardless of why they had stoma surgery in the first place. It was this that prompted me to submit my story to *Tidings*, as I thought people might be able to learn from my experience.

Bowel problems have plagued me most of my adult life. I was assured on a number of occasions that it was because I had Irritable Bowel Syndrome. Like many people with the condition, I made adjustments to my diet in the hope that this would alleviate my symptoms. During 2017 things however changed. I started to see blood when I passed motions and the frequency with which I needed to visit the toilet increased. I also noticed that I had a lump in my back passage, which I thought was probably a haemorrhoid. When I visited the GP she thought it was a polyp and arranged for a colonoscopy. Subsequently the polyp was removed and found to be cancerous. Mr Benziger, the consultant I saw, was very 'to the point' and advised me that the best option to prevent the cancer spreading was to have my anus, rectum and part of my colon removed and a stoma formed.

Once I had recovered from the initial shock, I realised that I had to give thought to the future after surgery and changes I might

need to make to my lifestyle. Luckily, a number of people I knew had friends and relatives with stomas. I was able to talk to them and managed to get lots of advice and guidance. I really appreciated this as it helped me to prepare for the surgery. From the start I decided to be up front with friends and also my colleagues at work. When I started telling people about the surgery I was going to have, I discovered that one of my co-workers didn't even know what a stoma was. Being able to explain to them was of course a good thing, because it helped them to be more understanding of my needs later down the line when I returned to work afterwards.

I had my surgery at the end of September 2017. It was a seven-hour operation. The following day as I was recovering, one of the stoma nurses visited me and asked if I wanted to see my stoma. When I said "yes" this surprised her. She said that some of her patients found it so difficult to accept their stoma and what had happened to them, they wouldn't even look at it for the first few days. But I took the view that it was part of me so I had to look and learn the start of a new routine. I named my stoma Cherry due to its colour and shape. The day prior to my leaving hospital one of the stoma nurses came to see me and said I was "an inspiration" as I was coping so well and had accepted my stoma with no problem.

It was found that one of the 23 lymph nodes removed was also cancerous and preventative chemo was suggested. This started in January 2018, but the second

session didn't go well and was aborted. Due to various problems I was at the hospital for nine hours, having two lots of Piriton and saline by drip. After this experience I decided I could take no more. So, instead of continuing with the chemo, I went for regular scans and blood tests and seeing the consultant on a six-monthly basis. This will continue until 2023.

Towards the end of 2017 I had sufficiently recovered to know that it was time to be brave and start the process of getting my life back on track. First steps included attending the quizzes my husband and I support, a trip to the theatre in town (as we had bought tickets before I had the operation) and out for the occasional meal. I know that many people struggle in the early days and have concerns about managing their stoma when they are out and about. Thankfully, this wasn't me and there were no hiccups as I made my comeback. All I will say, is that locating the nearest accessible toilet in case I needed to change a pouch was my first task on any trip! I have subsequently discovered the RADAR key and certainly recommend getting one. It was really useful on the first lengthy car trip I made in June 2018, which included the M25 on Ladies' Day at Ascot and needing to use the motorway services to change a pouch. It allowed me immediate use of an accessible toilet equipped with a clinical waste bin.

When I was around four months post-op I started to think about returning to work. I am a legal secretary and the office is some 15 miles from home. The prospect was



daunting. As well as my stoma to consider, by this time I had the start of a parastomal hernia to contend with, as well as phases of depression and occasional panic attacks. I was also concerned about how I would manage to fit routine hospital visits around work. Rather than keep all this to myself I decided to be as open as I could with my boss. I believe that this was the right approach. He was very understanding and it was agreed I would initially return for three or four mornings a week and build from there.

Although it was reassuring to know that I could dictate the pace of my return, I was still very apprehensive about going back. My mind was constantly filled with questions and thoughts, mainly around managing my stoma and the reaction of colleagues should I have a mishap: What if Cherry works overtime and I need to change a pouch? How will I dispose of it? What if I have bouts of wind? Will others stare at me or ask questions? How much information do I give? What if I feel depressed and cannot cope? Must remember to take my kit etc. I'm sure that such worries are common to all ostomates. My advice is to talk to your employer and also talk to your colleagues. This can be difficult, but I believe that doing so aided my return.

Right from the start everybody was fine, caring and helpful, but this didn't stop me having a few wobbles in the early days. Looking back I can see that this was perfectly understandable given what I'd been through, but at the time I wasn't able to step back in this way and think so rationally. If you are about to return to work, then try to remember this and don't let something small that happens get out of proportion! For example, the first time I had to change a pouch at work I initially panicked but then thought I have to deal with this. After all, Cherry was part of my way of life now. After I had changed the pouch I realised that the usual bins in the Ladies were not for this sort of clinical waste. So I went outside and placed the black bag in the council refuse bin. I couldn't think what else to do. My next worry was about changing my pouch when another member of staff was in the next cubicle. Even though I routinely sprayed the bag and cubicle I thought "What if there is a smell?" Again, I soon realised I was panicking unnecessarily. Having told people what I'd been through, they knew the situation and, what's more, there are sometimes smells in toilets!

Overall, I soon got back into the swing of things (although on my first day back I couldn't remember my password to log on

to the computer!). If you are at the point of thinking about a return to work yourself then I encourage you to talk to your employer and also to your work colleagues. It certainly helped me and has continued to do so. I learned from talking to one of the accounts staff, that by law an employer is required to provide a clinical waste bin should any full-time member of staff have a stoma. Whether this is correct I'm not sure, but days after I raised the matter my own clinical waste bin was delivered. This was much better than going outside to put the black bag in the public bin! Additionally, because people know about my situation, it has been easier to make adjustments to my role. For example, one of the other secretaries has happily taken on most of the filing. This is great because it means I don't have to worry about over exerting myself lifting heavy files. As you can probably imagine, they can be quite hefty in a solicitors' practice.

If you are about to return to work then I hope reading about my experience will help make your return just a little easier. As I said at the start, I'm now counting down to my retirement and as I write this, have just reduced my hours and am now working just four days a week. This means I no longer have to worry about fitting in those hospital visits! ■

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*Our team are registered with the CQC (Care Quality Commission) who independently monitor the care we provide.
1. Walker et. al. Raising the bar: new flexible convex ostomy appliance – a randomised controlled trial. WCET supplement 2016

Colostomy UK: active ostomates



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



#Stoma66

Introducing Stoma 66!

Last year our 50K Challenge encouraged people with a stoma, their friends, family members and healthcare professionals to get fit, along the way smashing our target of 50,000 kilometres and demonstrating that having a stoma need not be a barrier to achieving anything. It ran from April to October and to say we were blown away by the results is an understatement. 356 of you helped us rocket through the 50K barrier. Together we reached a staggering 69,739 kilometres.

One of the great benefits of the challenge was the number of participants who stayed active after it finished. Research shows that on average it takes 66 days to form a lasting habit. This means if we can get you active for 66 days then there's a good chance you'll carry on being active afterwards. So this year our challenge is focused on getting you active and keeping you active. That's why we've called it: **Stoma 66!** And, as a little incentive, we'd like you to help us reach an even bigger target this year of 66,000 kilometres.

Being active on a regular basis is important because it can help reduce the risk of developing cardiovascular diseases. If you're overweight, exercise can help you reach and maintain a healthy weight, thus reducing the risk of diabetes and heart disease too. Maintaining a healthy weight is also important for the health of your stoma.

Exercise is also good for your mental health and well-being. This is particularly important given that some ostomates struggle with anxiety and depression. Regular exercise can help reduce stress and anxiety, which can only be a positive thing.

The good news is that you don't have to be afraid of getting active. There are plenty of things you can do that are suitable for you, whatever your age or fitness levels, and you can try them on your own or as part of a group. It could be gardening, walking the dog or even dancing!

Stoma 66 runs from September 16 to November 20 so there is plenty of time for you to get involved. It is free to register, just visit www.ColostomyUK.org or call us on **0118 939 1537**.

Everyone receives a challenge pack, with the first 500 people to register getting a **Colostomy UK** Stoma 66 t-shirt and pedometer too! Finally...don't forget to look out for AND SHARE #Stoma66. Let's see if we can get it trending.

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

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



Rugby league update

At the time of writing our Rugby League team have played three games so far this year and we're really proud of the impact each one has had both on and off the pitch.

Back in June we visited the Chorley Panthers and had a fabulous day on what is now planned to be an annual event. A crowd of over 400 were joined by several high profile sportsmen who came along to show their support for us. This included Rugby League players Josh Charnley of Warrington Wolves and England, Jamie Ellis from Castleford Tigers, plus Owen Farnworth and Anthony Gelling from Widnes Vikings, and undefeated pro boxer Jack Catterall. Both the size of the crowd and the profile of some of those in attendance highlights how the team are raising awareness in the wider world of what it is like 'living with a stoma'.

In August we journeyed over the Pennines to Leeds and took on the Political Animals at the home of Bramley Buffaloes. The Animals are a club comprising politicians at all levels and from all political backgrounds.

We'd like to say thanks to everyone from Chorley Panthers, Bramley Buffaloes, and the Political Animals for their support in making these two games such a success. Especially Kaven Ellison, Martyn Cheney, and Mark Ramsdale. If you'd like to find out more about our Rugby League project including playing, volunteering, or spectating please e-mail Giovanni.Cinque@ColostomyUK.org or call **0118 939 1537**.

Our last game of 2019 is on 9 November when we take on Aldershot and Fleet Masters in Hampshire.

#ActiveOstomates



Active Ostomates and support groups

Since the start of the project in 2016 we have delivered nearly 200 chair yoga, archery, art, and swimming sessions to over 3,000 people through stoma support groups. Since the last edition of *Tidings*, groups in areas from the north east through to Yorkshire, the Midlands, the south east, Bristol and Devon have benefited from our free programmes. In August we were delighted to deliver our first chair yoga session in Scotland, through the Glasgow Stoma Support group.

September also saw us hold our fourth swim event of the year in partnership with the East Berkshire Ostomy Club (EBOC) and The Windsor, Ascot, Maidenhead & Slough Stoma support group (WAMS). It follows on from earlier successful dates in Londonderry, Leicester, and Liverpool.

We know that many ostomates worry about getting in the pool, so our closed sessions are a great opportunity to take a dip in a friendly, supportive environment. We're always looking for new venues so if you have any suggestions or would like to help us run a swimming session in your area please get in touch.

If you run a support group and would like to join our Active Ostomate programme, or just want to find out what sessions are being run near you please call **0118 939 1537** or e-mail: **Giovanni.Cinque@ColostomyUK.org**



Revised literature

Revised and updated *Active Ostomates Sport and Fitness after stoma surgery* booklet available.

We have distributed over 8,000 copies of our *Active ostomates: sport and fitness after stoma surgery* booklet since its launch in 2016.

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

To get hold of your copy either download it for free from our website, call us on: **0118 939 1537** or send an e-mail to: **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.






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Life is for Living

Richard Jordan

It all started in summer 2001; I was 38 years old and a very busy carpenter working on building sites. I was working too many hours and definitely didn't have time to be ill (in my mind at least!). I remember many times urgently running to the loo, to find nothing but a small splatter. As you do, I carried on as normal, back to work for me. I put it down to piles and ignored it for about six months (more fool me). I remember in December I had the 'big one'. While at home I had to run to the loo, just making it in time, only to find afterwards I had filled the toilet with blood. Following this I went to see my GP, on went his gloves and from then on my world changed!

Christmas wasn't great (an understatement – as I am sure you can well imagine!). My hospital results were due the first week in January. January came and so did my appointment. I was called into the side room with my girlfriend: "You have a mass the size of a bag of sugar..." and "...yes it's cancer". I asked would I be OK? And was told they couldn't say. At this point the doctor was not able to give me any advice about surgery, as it depended on how

I responded to the chemotherapy and radiotherapy. I walked out of that room in complete and utter shock, is this really happening to me? I doubt I will ever forget that day, I still remember it so vividly.

For me it was important to understand the treatment and the reality of it all. With the tumour being located at the exit of my bowel, I was told that if surgeons could operate and treatment was successful, I would be left with a permanent stoma. I had two weeks to process the news before commencing treatment and what a roller coaster of emotions it was: tears, self-pity, anger and finally acceptance of the illness and the willpower to fight it. And, before I knew it, six months of chemo followed. I also knew that after this a month of daily radiotherapy awaited.

I asked medical staff how unwell I would feel during the treatment and was told that I would be so tired that I would struggle to even walk my dog! As a keen Motocross rider and cyclist, this was hard to accept. I decided I was going to push hard to keep up my fitness and even carry on racing. So with my chemo bottle in my back pack and

the pipes duct taped to my body armour, I waited on the start line to race (no one would have ever known). I even cycled a 20-mile round trip to the hospital for my chemo bottle to be changed! In my opinion, exercise was the most important thing for my body and mind. Yes, there were side effects: sore hands, bleeding feet/finger, toe nails as thin as paper and bleeding, the delayed effects from radiotherapy were far worse, but all bearable.

After finishing all my chemo and radiotherapy, I had a small explorative operation. This was the big day I'd find out my options; surgery or palliative care. When I came around from the anaesthetic I was surrounded by happy smiling faces: "Great news the treatment was a great success". Thankfully, the tumour had shrunk to nothing, but surgery was still needed to be sure.

I looked at my new stoma as my friend, a life saver. I had also been doing research about colostomy irrigation and knew if I

CONTINUED ON PAGE 17, COLUMN 1



Looking for online support?

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

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

We look forward to welcoming you.

www.ColostomyUK.org

Stoma helpline:

0800 328 4257

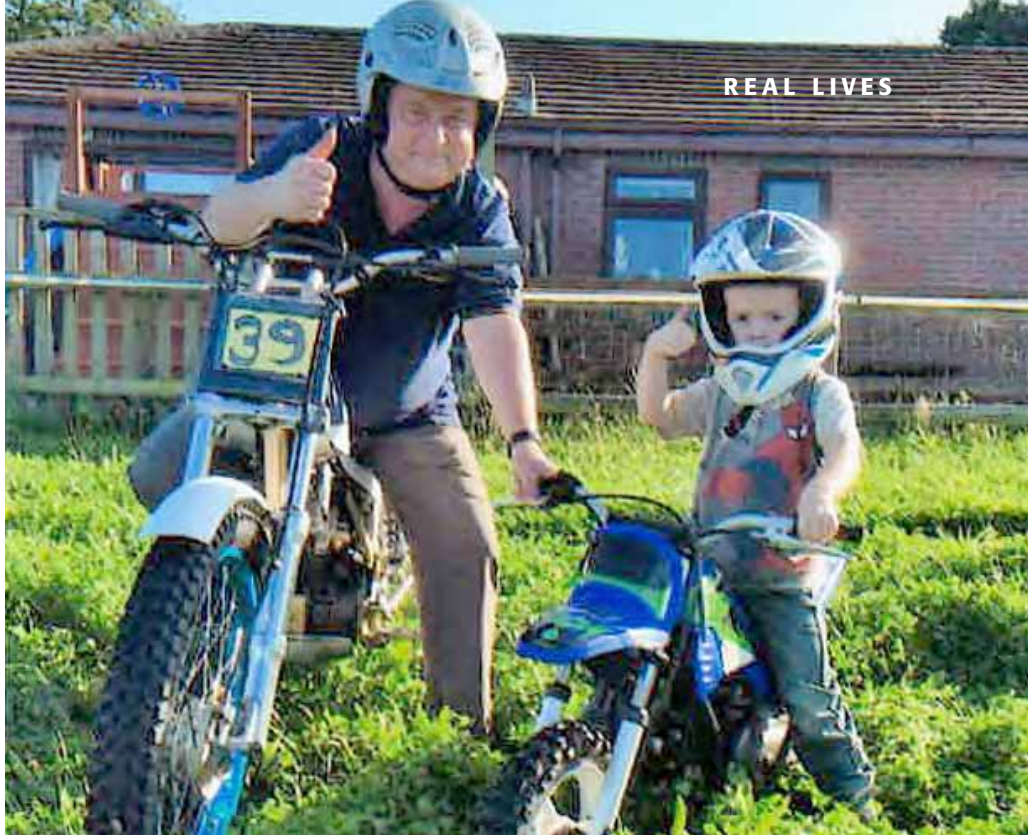


CONTINUED FROM PAGE 15 COLUMN 3

could master this, I would be able to carry on with my racing. So, three weeks after surgery and three pairs of padded shorts later, I was back on my mountain bike and three months after that I was back racing Motocross.

Learning to irrigate was also coming along well, the best advice I can give (if you are interested) is learning how to do this needs patience, logical thinking and, in the early days a bucket of soapy water and a sponge to clean up those mistakes! It took me about six months to fully master irrigation. For me it's been the best thing; the perseverance was certainly worth it. I have no excrement sat there in a bag, just a small 76mm stoma cap. What's more, the whole process takes me no more than 20 minutes per day!

The next goal was to race in an off road motorcycle event over the Pyrenees in Spain, this was a two day event, eight hours a day in the saddle of the bike in the July heat and, just to make it harder...in the middle of a heat wave 42°C hot at midday! The sweat and dust were a bad mix for my stoma, meaning I stopped every two hours to change my stoma cap. I didn't always make it in time and the cap was gone, resulting in cleaning up with the water from my drinks bladder but, once sorted I was



off again. Since this event I have completed a further three events and I'm planning my next event as I write this, all whilst carrying on with my classic Motocross.

Now at 56 years old I feel so very lucky to have been through this experience. It has opened up my mind to life and made me more aware of other people's lives and

problems. Now I say that if a problem won't change your life and will be forgotten in six months, it's simply not worth worrying about. Life is for living, everyone has problems in their life, some bigger, some smaller but all very important to the person living with them. ■

Colostomy Irrigation and You DVD

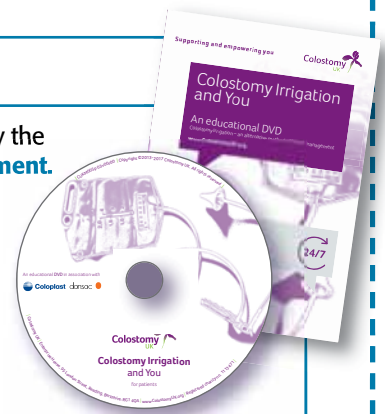
Order Form Colostomy Irrigation and You (Patients)

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 can irrigate. It is therefore essential in the first instance to consult your surgeon/stoma care nurse as they will advise as to your suitability.

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

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



Title: _____

Name: _____

Address: _____

Postcode: _____

Tel: _____

Email: _____

Please allow 30 days for delivery.

Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA Charity No. 1113471 VAT No. 917079312

T55

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

A large graphic celebrating 30 years. It features a blue and green gradient background with confetti, streamers, and stars. A large '30' is centered in a light green circle. Below it, the text 'thanks for an amazing' is in white, and '30 years' is in a very large white font.

30 thanks for an amazing 30 years

This November marks the 30th anniversary of the Medilink® Dispensing and Home Delivery Service. From just one location, we have grown to provide a truly personalised service over the phone, in homes and face-to-face in 19 dispensing care centres nationwide.

We'd like to take this opportunity to say a big thank you to our loyal customers and staff for helping us reach this important milestone.

Be part of the celebrations and share your Medilink® memories by emailing us on celebrate@saltsmedilink.co.uk

**Supporting you every step of the way
because you deserve exceptional service**

To find out more about the Medilink® Dispensing and Home Delivery Service, please contact:

FREEPHONE 0800 626388

(Monday to Saturday, 9am – 5pm)

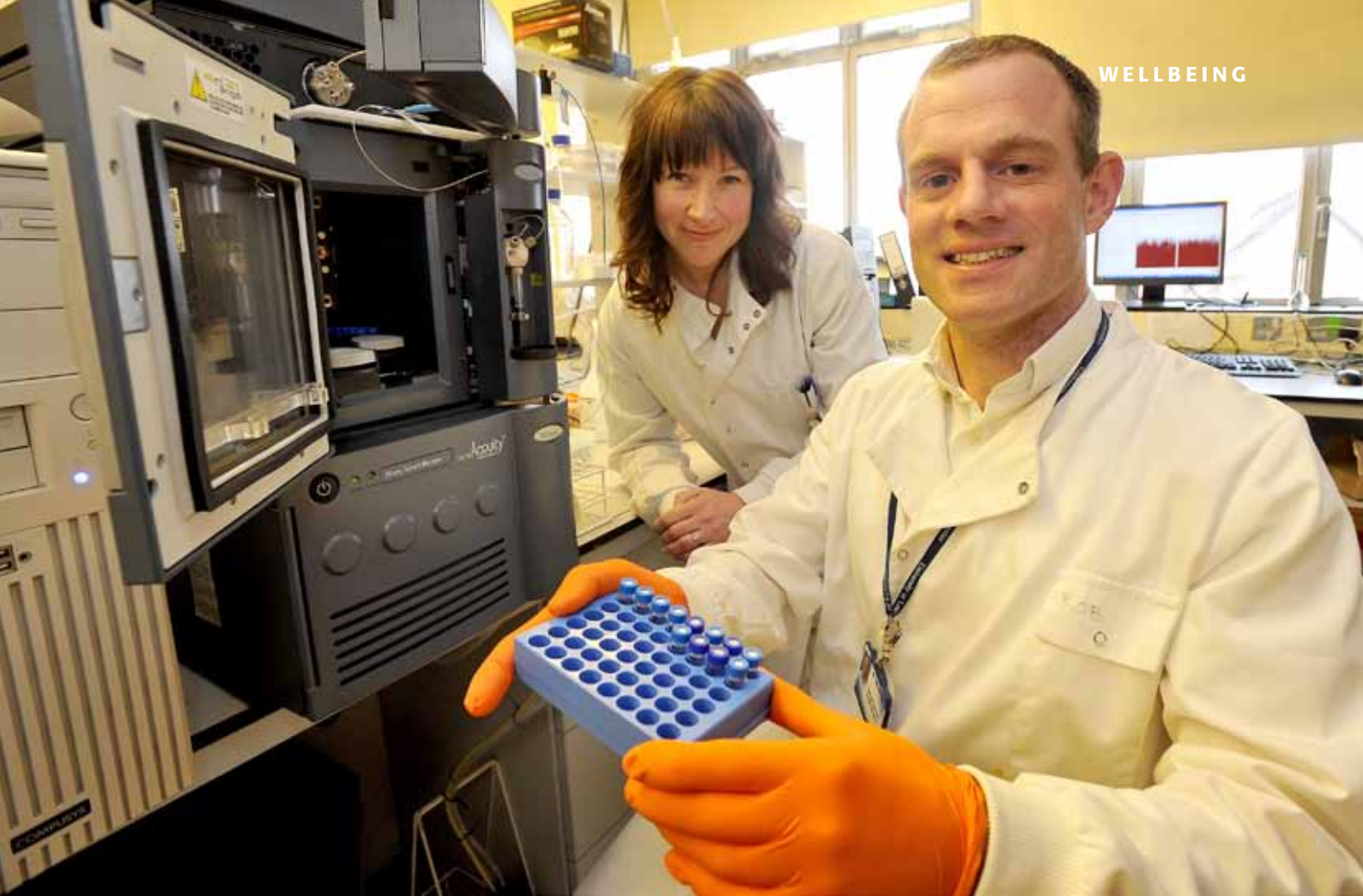
Email: enquiries@saltsmedilink.co.uk

Web: www.saltsmedilink.co.uk

Follow us:  @SaltsMedilink  SaltsMedilink



medilink®



BDRF

Bowel Disease Research Foundation

Glen Saffery
Research Coordinator

Bowel Disease Research Foundation (BDRF) exists to fund research into bowel disease with a clear purpose – to improve the lives of people affected by bowel cancer, IBD and other bowel disorders both right now and in the future.

BDRF is the charity arm of the Association of Coloproctology of Great Britain & Ireland (ACGBI) – the professional association for colorectal surgeons and specialist nurses working in the British Isles. So the chances are, if you've had surgery on your bowels, you were probably operated on and cared for by members of this association.

It's easy to think of research as something that happens in a laboratory, done by people with white coats, microscopes and petri dishes – but a huge amount of our work is practical and focussed on day-to-day life both in and out of hospital.

We believe our research has a massive role to play in making sure people with a stoma

get the best possible support and care – before, during and after surgery.

We're delighted to be contributing to *Tidings* – and would love to hear from you on what you want to read about from our research in future issues.

What we do – prioritisation and ongoing studies

In the last few years, we've been bringing surgeons, nurses, patients and fellow charities together to define what our research priorities should be – shaping our agenda for the research we fund. Through a series of interactive workshops, online voting and public surveys, we were able to develop a list of priority research questions for researchers to begin to tackle.

It goes without saying that life with a stoma comes with its own unique set of

challenges – be they physical, emotional or psychological as people adjust to such a major change.

Unsurprisingly, improving quality of life for people with a stoma – particularly reducing and alleviating feared complications like parastomal hernia – consistently featured as a major priority for patients and healthcare professionals alike during this process.

In a particularly important and ground-breaking moment, patients and surgeons discussed attitudes toward stoma surgery – whether this constituted a 'failure' in treatment or 'last resort', and how this sort of language can make people feel. Many of the medical professionals in the room had their attitudes and approaches completely changed, and research has subsequently been developed to address communication and stigma.

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Do something amazing!

Join Team Colostomy UK.

Together we can make a difference.

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



fundraising@ColostomyUK.org
0118 939 1537

ColostomyUK.org



CONTINUED FROM PAGE 19 COLUMN 3

The process helped to launch the CIPHER Study, a major national trial looking at the best method of surgery to form a stoma and reduce the likelihood of a parastomal hernia.

We've also funded work focussed on cancer patients' attitude towards potentially having a stoma and how this affects their treatment preferences. It is an innovative attempt to answer some of the pressing questions around treatment from a patient point of view, and we hope will help inform healthcare professionals about what factors patients find important when making decisions about their treatment.

In the last two years, we've teamed up with our friends and colleagues at the Ileostomy Association and Kingston Trust to fund even more research.

These projects look at major aspects of everyday life. A team in Scotland are looking at exercise as a method of reducing the risk of parastomal hernia, aiming to show that patients can safely take part in a wide range of physical exercises, removing a lot of the fear and stigma around an active

lifestyle with a stoma and freeing people to enjoy their lives as they wish.

Excitingly, we've even funded a study led for the first time by an ileostomy patient. Her work will assess what expectant mothers with a stoma experience when wanting to start a family, while they're pregnant, and after delivery. This will help make sure future patients have much better information to help them make decisions.

What would you like to know?

We'd like you to be part our research – and to let us know what aspects of our work you want to read about in future issues of *Tidings*. Research studies? Interviews with surgeons and nurses? Perhaps stories from patients involved in our research?

At a recent conference, we ran a campaign called **#BowelHopesAndFears**. In it, we asked conference attendees and our social media followers to let us know what they hope to see achieved through research, and what obstacles might hold it back.

You can help us fuel conversations about what are the most important areas to address in our research and help sharpen our focus.

You can read more about that campaign, and how to contribute, by following us on Twitter (**@BDRF1**) and on Facebook or on our website at: **www.bdrf.org.uk/news/ceoblog/hopesandfears**

We know that research has a huge part to play in tackling the daily challenges of life with a stoma, developing knowledge that helps people live their lives to the absolute full.

Please let us know what you'd like to hear about in future, and we'll do our best to oblige!

You can contact BDRF directly via Glen Saffery, Research Coordinator:

e-mail: **gsaffery@bdrf.org.uk**
Twitter: **@BDRF1**
Facebook: **www.facebook.com/BDRFCharity**

Your travel checklist

On top of all the normal precautions, like making sure your travel documents are in order, take copies of important documents with you in case the originals get lost or stolen.

The ostomate needs to remember to:

- Pack sufficient supplies for your stay. At least twice the normal usage at home.
- Take all supplies and travel stoma kit as hand luggage.
- Ask the airline in advance if you need extra hand baggage for your supplies.
- Avoid food and drink that are likely to cause upset or excessive wind the day before you travel.
- Pack all your normal medications and any that may help an upset stomach.
- Pack some form of electrolyte replacement solution in case you become dehydrated.
- Drink bottled water, avoid ice in drinks and use boiled or bottled water to clean around your stoma, and to irrigate in countries where water could be contaminated.
- Store your supplies in a cool place, out of direct sunlight.
- 'Check in' online 24 hours before departure to secure your preferred seat.

Remember:

- ❖ You can request **not** to go through a body scanner but if you do, you **WILL** be subjected to a full search.
- ❖ Most UK airports now operate a hidden conditions lanyard or bracelet scheme. These are available from assistance reception areas. Wearing them identifies you to staff as having additional needs.
- ❖ If you need assistance on your flight you should advise your airline at least 48 hours before your departure date.
- ❖ You should **AVOID** requesting the presence of a healthcare professional if you are searched. Airports do not generally have such staff on standby and the likelihood is that you will miss your flight.
- ❖ You can only take more than 100ml of liquids in your hand luggage if there is a prescription label on said item.
- ❖ You should expect to be treated the same as everyone else. Having a stoma does not exclude you from any security checks.



General Enquiries:
0118 939 1537
Monday to Thursday
9am – 5pm and
Friday 9am – 3pm
or
E-mail:
info@ColostomyUK.org
Website:
www.ColostomyUK.org

Irrigation and you



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

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



Fear, fun and finding your feet...

all part of the experience PART TWO

Trevor Alexander

In the last issue of *Tidings*, Trevor wrote about his cancer diagnosis and how he came to terms with having a stoma. He ended with the words: "my friend gave me a copy of *Tidings* and I discovered..." what he discovered was that irrigation was the solution to his problems of irregular output and pancaking...

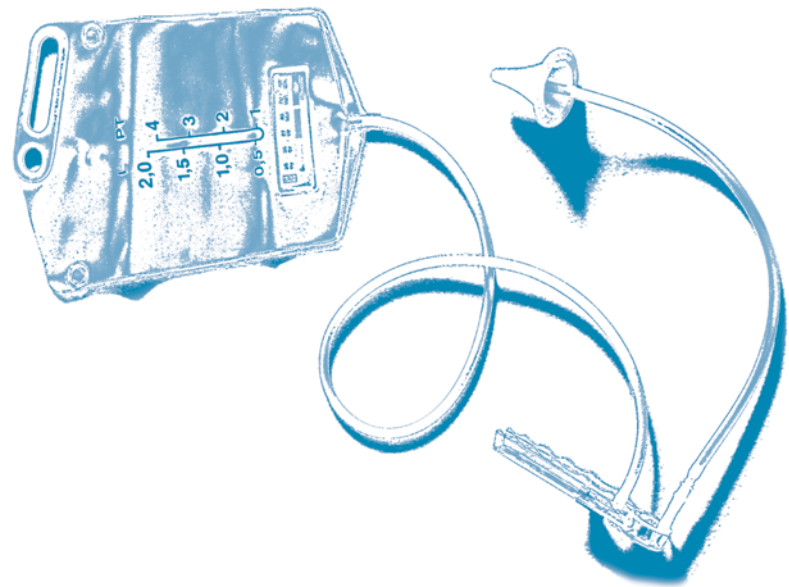
I spoke to my stoma nurse to find that few people in the area irrigated, but she explained the process and agreed to order me a kit and let me try. When it arrived from Coloplast she gave me a lesson on how to put it together and supervised me using it. When she was happy I was competent, I was sent away to try on my own. My initial solo effort was a little like going back to the beginning again. Firstly, the reservoir had to be filled with water at the right temperature, sounds easy in theory but in practice proved to be anything but! The reservoir outlet also has to be positioned at least shoulder height and, as my bathroom hook wasn't, the first thing I had to do was to get a new hook. Unfortunately I didn't account for the weight of the reservoir (which starts with up to a litre and a half of water in it). So my advice is don't use a self-sticking hook. I made this mistake and when the hook fell off the wall just as I inserted the cone into my stoma there were some choice words as the bathroom flooded! I'm philosophical about this now. Like all new things a sense of humour is required when learning a new skill. Once a new hook was screwed into the wall I found the whole process a revelation. I eventually found the best reservoir support was the suction support from my car Sat Nav.

This can also be taken to hotels and attached to bathroom tiles; no hotel I've visited ever has a hook at the right height.

I have had several other interesting experiences apart from the kit falling off the wall. The worst one was self-inflicted when I went to Tenerife for two weeks and forgot to take the plastic sleeves that act as a chute for the waste to fall into the toilet. Amazing what can be engineered with a pedal bin liner. You can see why a sense of humour is necessary!

The irrigation system has revolutionised my situation. Now, to a large part, I am back in control of my life again. Once I had got used to the process (which is very easy) it meant I could use it at a time to suit me and be confident for the next 24 hours at least. There are less obvious advantages too. Large bags can be discarded and I now use mini bags which are much more comfortable and easily take care of any small discharge that may happen occasionally during the day. This is quite rare and is usually self-inflicted by eating something silly or drinking too much red wine! I will not go into the process of irrigating in any detail as this is much better explained by a professional, but rest assured it is quite painless!

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



The first six months of irrigating were successful, but there were a couple of drawbacks. I found that the reservoir was quite a clumsy piece of equipment and sometimes the water flow was slow or erratic. The flow could be controlled by a trigger mechanism with a visual plastic spinner, but sometimes, even when fully open, I had trouble with the flow into my stoma.

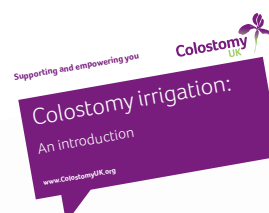
The final piece of the jigsaw fell into place when I read a short readers letter in *Tidings* which recommended an irrigation pump. The one in the letter was made by B.Braun so I visited their website, had a look and sent for the information brochure. To buy the pump is quite expensive (approximately £500) but I discovered that it was available on prescription with my doctor's approval. This didn't prove to be as straightforward as I had hoped, because my GP practice had never been approached for one before. My telling them how good I thought it would be didn't cut much ice and initially I was politely told 'no'. However, I am nothing if not persistent and contacted the local rep for B.Braun who was incredibly helpful and set up a meeting with both my doctor and my stoma nurse. This helped them to appreciate the benefits of the pump and eventually resulted in one being provided on prescription.

The pump proved to be the answer to both the problems I had encountered and also considerably cut down the time required. I don't wish to be seen as a salesman for B.Braun Iry Pump but it is a superb piece of equipment and the service has been magnificent. The pump decided to stop charging when I was touring Italy last year and after a phone call a new pump was dispatched and was at my next hotel the following day.

So that's my story! I'm sure some of the issues will be familiar to others. It's now three years since my operation and I can honestly say that since I have moved onto irrigation with the pump I have never looked back. If you have never tried irrigation I would recommend you give it some serious thought and give it a try, maybe with a kit first. It's a discipline which I have found easy. It takes me about 30 minutes from start to finish and has become an add on in the morning before my shower.

I'm now looking forward to the ten years that Mr Slater, my consultant, promised me!

Trevor Alexander
Newcastle-upon-Tyne



Revised literature

Revised and updated
Colostomy Irrigation:
***An Introduction* booklet**
available.

The newly revised and updated version is now available. To get hold of your copy either download it for free from our website, call us on: **0118 939 1537** or send an e-mail to: **info@ColostomyUK.org**



Nobody would claim that stoma surgery is a walk in the park. The body can take months to heal. Ongoing stoma management is the next concern as well as dealing with the likes of leakage and sore skin. Issues which, as we know, have a habit of returning with changes in body weight and stoma size. Thankfully, there is plenty of help out there. As editor of *Tidings* I am fortunate enough to have access to every edition since the magazine's launch in 1998. I can tell you, it is a treasure trove. In fact, it is testimony to the wider efforts made over the past two decades to make things just a little easier for each new ostomate.

And, this quest goes on. Surgical techniques keep developing. Ostomates continue to draw on the collective experience of our volunteers. As a charity we are also involved in research on everything from parastomal hernias (CIPHER study) to pancaking. The stoma companies continue to play their part too; think of bag technology and how the latest designs have moved on from those described by Lynda on page 28.

However, there is another side to having a stoma which, until very recently, was rarely spoken about...and that's the affect it can have on mental health. The silence has much to do with the general stigma surrounding mental illness, the edifice of which has only recently started to crumble. But progress is being made. The positive links between being active and mental wellbeing are now widely acknowledged. Indeed, research findings in this area have been important shaping **Colostomy UK's**

Active Ostomates project and the recent addition of creative minds art sessions to our offering. But, despite these advances, we would be the first to concede that more needs to be done, both to understand the impact that stoma surgery can have on mental health and to help those that suffer. Moving forward, everyone needs to work towards creating an environment where mental health can be spoken about openly. This will need courageous people. People willing to share their experiences, people like Vicky Sykes, who I had the pleasure of interviewing a few months back.



Vicky is 44 years old and has two stomas. She has named them 'Ping' and 'Pong', hence the title of this article and the rather esoteric front cover to this *Tidings*. Her story illustrates perfectly why we need to get better at talking about mental health and stomas. Vicky's story began when she was 25 years old and suffered a spinal injury. This occurred from a simple, but tragic accident. Her son, who was a baby at the time, had just woken up and Vicky was carrying him downstairs, when she lost her footing. The injuries she sustained didn't require emergency stoma surgery. Indeed, Vicky had her loop colostomy 14 years later. It was performed as the final option, after other procedures and medication had failed. This gave Vicky plenty of time to research what the surgery entailed. But, as she said, you can only prepare so far and she still remembers waking up afterwards, seeing her stoma and thinking: "I can't do this!"

Of course this is not an uncommon reaction. Nor were Vicky's subsequent

feelings of relief when she mastered bag changing. Shortly afterwards, buoyed by how she was coping, Vicky made her first trip out. But an incident at weight watchers changed everything and made Vicky realise that she was far from recovered: "I was sitting there and my bag made a noise. I was mortified, but tried to act normal and ignore it...that was until the people by me laughed and made unpleasant comments. I left in tears, not wanting to return or, in fact, leave the house for fear of this happening again". Vicky found herself in a situation where her body was healing well but mentally, (to use her own words), she was a "mess". She worried constantly about leakage, noise and smells. She also started to develop irrational fears about using public toilets. Bag changing wasn't the issue. Instead Vicky worried what people using the facilities after her might think. I'm sure many readers will be able to relate to how Vicky felt at this time. But in Vicky's case, it led to her becoming a virtual recluse.

Vicky can't put her finger on a particular moment or incident but, over time, something changed. Perhaps the critical thing was that she began to accept there was a problem. This led eventually to Vicky giving herself "a good talking to". I told myself: "So what! I have a bag. We all go to the toilet; I just do it in a different way". As this fresh mind set became embedded Vicky started to cope again, helped by the ever present support of her family. As a mark of how far she had come, she plucked up the courage to go on holiday and even took the brave step of wearing a bikini. Vicky says that although she still harboured paranoid thoughts, she had recognised that if she didn't start to think and act differently, then her stoma was

My two stomas 'Ping' and 'Pong'

Vicky Sykes



going to take away her life. It might have helped her 'physical' body, but it was in danger of destroying her mental wellbeing and sense of 'self'.

Sadly, as Vicky started to cope, so it became clear that her loop colostomy had not resolved all the problems from her spinal injury. In 2018 she was told that she would need a bladder diversion and a second stoma (urostomy). This was a great shock and a devastating blow. But Vicky says she still managed to stay positive (at least at first). Despite dreading the thought of more major surgery, she was doing well with her first stoma and thought: "If I can cope with one, I can cope with two". However, Vicky found things much more difficult second time round. She suffered with infections and soreness. She also quickly discovered that management and care of a urostomy is more intense than a colostomy. It took a while to find the right bag and all the while she was leaking daily and the skin around her new stoma was sore with blisters. Hearing this, I wasn't really surprised when Vicky said that all her old fears returned and "with full force sent her flying backwards". So much so, that she began to push away her family, who were desperately trying to support her as best they could: "they would say to me 'you are what you are' and 'what you have makes you' – but to me these were just words".

The physical recovery was slower this time round. Its impact on Vicky's mental health can be measured by the fact that she was pleased. When she said this I was taken aback, immediately wondering why this was the case? Vicky explained: "I was glad my recovery was slow as I saw this as a way of living in my little bubble and hiding away from the outside world. Just walking to the local shop was a challenge. I would

look down at my stomach area and think everyone would hear the urine". As Vicky's body started to heal, her mental struggles intensified: "I would wear layers of clothes and hold my stomach to hide the two bags, even though I knew they were covered. I constantly gave excuses to my family and friends if I got invited out. I remember doing the first post-op school run. I got to the school and just wanted to turn round and run back home. I sat in my car frozen, I couldn't move. My son had to be taken into school by another mum".

This was a very dark time for Vicky. Her relationship with her husband also started to suffer, as she found herself wanting to hide away from the man who loved her. Perhaps it was this that triggered something in Vicky again. She began to realise what was at stake and that if she didn't act, then she risked losing everything. Just like before, Vicky made the decision to fight her negative thoughts and grasp back her life. I asked her how she managed to do this and her answer was: "Little steps. One day at a time". One strategy she developed was to try and change one negative thought into two positive thoughts in the hope that this would help her to begin embracing life with two stomas. It was this that led to the naming of her stomas 'Ping' and 'Pong'. She also did her best to imagine what her life would have been like if she had tried to carry on without having stoma surgery. Gradually her efforts paid off, although Vicky was at pains to point out that the road wasn't straight and level, but bendy and with plenty of dips. Thankfully, Vicky is

now in a better place and firmly believes that mental scars can heal just like physical ones. If you are suffering then her advice is simple: no matter how hard it is, try to pluck up the courage to talk to people around you about how you are feeling, rather than hiding away.

Vicky was keen that people learn from her experiences. From my point of view she has succeeded. Vicky's story helped me to appreciate the far reaching implications that poor mental health can have, not just for the sufferer but for those around them. This reinforced my view that more needs to be done, with mental wellbeing figuring just as prominently as physical wellbeing in the aftermath of stoma surgery. This means talking about the fact that mental health can take a knock and equipping patients and their families accordingly – both to spot the signs and to know what interventions are available. The coping strategies that Vicky developed also spoke to me about the responsibility we have for our physical and mental health. Finally, Vicky's incident at weight watchers (which seemed to 'tip the balance' of an otherwise promising recovery), made me realise how important it is that **Colostomy UK** continues to raise awareness through its 'Stoma Friendly Society' campaign. It's more than just seeking practical changes to things like public toilets (important as these are), it's also about educating people to think before giggling.



Written by
Richard Biddle

Our BIG Open Day: report



On a sunny day in late June the traffic halted in Telford. The birds stopped singing, people in the streets, shops, parks and bars paused, homes were quiet. The town wondered: "who are all these visitors heading to the International Centre, what's this vibe?" It was, of course, members of the ostomate community travelling from up and down the country to help us enjoy our BIG Open day. OK, perhaps I've exaggerated slightly, but one thing is certainly true...people did travel 'up' the country this time. Following feedback we moved our bi-annual event to a more geographically central location. Telford was a good choice also, because it gave us a chance to increase the visibility of **Colostomy UK** in Shropshire.

As we hoped, our BIG Open Day turned out to be a fun and friendly event. Mandi Laing, our new chairperson, got proceedings underway. She was followed by our president, Ian Daniels FRCS (consultant colorectal and general surgeon), who gave an interesting talk about stomas and stoma surgery. Attendees were then free to visit the exhibitors' stands, participate in the various workshops we ran, grab a coffee and chat to friends, or say "hello" to the **Colostomy UK** team! The collage of pictures should give you a good idea of what went on. There was a chance to try out chair yoga, explore one's creative side through one of our Creative Minds sessions, or put questions about diet and nutrition to dietician Sophie Medlin. The security team from Manchester Airport and Customer Assistance providers Omiserv were also on hand to answer questions about air travel and airport security. Finally, if that wasn't enough, there were appointments with stoma care nurses available.





For those that were able to stay, we rounded the day off with an Ostomate Fashion Show followed by a delicious evening meal. As always, the fashion show, the theme of which was 'The Four Seasons', proved very popular and we are grateful to ConvaTec for sponsoring this. Our models, all of whom had stomas, graced the catwalk in everything from formal attire to sportswear and received a well-deserved round of applause at the end. The evening was made all the more special as it gave us a chance to formally recognise and thank people for all they have done for the ostomate community. The stoma care team at Queen Alexandra Hospital Portsmouth, were presented with **Colostomy UK's** Purple Iris Award. **Colostomy UK** trustee, Alfred Levy received an award for his long-serving contribution both to our charity and also ostomates in the Stevenage area. Our volunteer Irene Constable received the award for the most active volunteer in the last year. As well as answering the stoma helpline and attending open days on our behalf, Irene runs BOTs support group in Oswestry, Shropshire and has been campaigning tirelessly over the past 12 months or so to make the area stoma friendly. Finally, Jo McKenzie, our Senior Support Coordinator, was recognised for her long service. She has worked for **Colostomy UK** for nearly 20 years now. Chances are, if you have ever called us, then it's Jo you will have spoken too!

Thank you to everyone that was able to come along, it was great to see you all!

Written by
Richard Biddle





January 1968: almost the end of the 'swinging sixties' and my final year at Secondary School. I was 15. I had been feeling unwell for some weeks now. Tummy pains almost every day, usually on my walk to school. Then blood in my faeces. The pains were getting worse and more frequent. Mum took me to the GP. Tests began. Hospital visits and those dreadful barium enemas and x-rays. I was soon admitted to Macclesfield Infirmary. Too old for the children's ward, I had to go on the adult ward. I was so frightened and alone as many of the patients were elderly women. The surgeons were trying desperately to stem the increase of symptoms with medication, including heavy doses of steroids and blood transfusions. The loss of blood was now quite heavy and I was going downhill fast. Their desperation was apparently the worry that, at that time, I would be the youngest person in the country to have 'the stoma'. I weighed four stone and time was running out. The operation was scheduled for 20 February 1968.

Following the operation, life was a blur. I had tubes, pipes and drips attached, and I was medicated into oblivion. I spent three months in that ward, in that hospital. My first 'bag' was a 'one-size fits all' foam ring, with a clear plastic bag threaded through and a hard white plastic ring to secure it. Then I had a belt to hold the whole thing

tight in the hope that nothing leaked. But IT DID, constantly! My skin was raw from leakage. Because the operation had been delayed so long, the ulcerative colitis (which was the cause of my illness) had got so bad that much of my bowel had to be removed. My stoma is thus sited almost level with my hip. This meant (and still does) that when I sat or bent it creased, causing leakage. At that time, the nurses used ether or meths to clean the skin, then applied tincture of benzene to dry the area. OUCH!!

I was depressed. I was in pain. My bag was leaking every day. I had been bed bound for so long my muscles were not working. I was stuck in a ward where people died because of their ages and conditions. My Mum and Dad visited daily (only two visitors at a time). The staff were amazing and tried many ways to improve the bag situation. The one thing that did cheer me up were occasional letters from Dorothy, who ran a fan club for Manchester United. I LOVED Man U and Georgie Best. But the Surgeons and nurses alike were very concerned. I was (apparently) dying. I was too weak to fight. But things were happening in the background...

One day, a couple of weeks after Dorothy visited me, I was hauled out of bed, clean nightie, hair brushed. Cleaners came and dusted and hoovered the ward to within an inch of its life. Screens were put round my

bed. Matron appeared and gave a nod of stern approval. Only then, after having been kept waiting sometime in the corridor, did my visitor come in. It was the great man, Bobby Charlton!

He told me to get well and come to a game to meet the players. He brought a card from George Best and some European pennants from the games United had played. They were in the final of the European Cup in May 1968. Bobby stayed almost an hour and chatted about football and me. Unbeknown to me, he gave me back my will to live and an excitement for the future. HE SAVED MY LIFE! I left hospital three days before the game in May 1968.

Three months later...and I was not coping well with the dreadful bags. A leak every night and most days wasn't doing my skin any good. I was never introduced to a stoma nurse, if indeed there were any, so had no support apart from the Ileostomy Association which could only be contacted via post. I can't remember who it was that advised me to change bag type, but I was grateful, even though I look back now on the period in horror. The new bag was a two-piece black rubber bag with a baseplate stuck on with a form of glue. To keep the bag in place there was a white belt, which attached to the baseplate. To empty the bag I had to unscrew a cap at the bottom (imagine the mess...). I did,

NEVER GIVE UP: From Bobby Charlton to family of three!

Lynda Smith



however, keep these bags for a number of years. As well as the belt securing the bag, I also wore the kind of sanitary pads which were secured using a belt (those were the days) so had to be careful not to unfasten the wrong belt ha ha!

That brings me to the next problem I had. The surgery left me with a vaginal fistulae. I didn't know this at the time. My periods didn't resume for some time, but when they did the secretions came both from the normal place and the hole that had been my back passage. This was because the fistulae was sited between the two. Normal sanitary protection wasn't quite enough and led to some awful, embarrassing, situations (never wear white became my mantra). I became quite good at adapting nappy liners and cotton wool to form a longer pad.

This fistulae caused the biggest heartache of my life. When I eventually found the man and the confidence to marry, I desperately wanted children. We were foster parents for a while and eventually adopted our daughter, but I could not conceive. Apparently, the fistulae was THE best contraceptive...I was under a brilliant gynaecological surgeon who undertook a procedure to repair the fistulae. This involved a kind of patchwork repair as the fistulae could not be sewn together. The operation wasn't too bad but the wound

had to be packed from what had been my back passage with paraffin packing. On leaving hospital this had to be replaced daily; a procedure that still brings tears to my eyes. Eventually though, life returned to normal.

We had been trying to conceive for around 17 years and, on reaching age 38, I was pretty sure it wasn't meant to be. Around this time I started to feel quite poorly, with dizziness and tiredness and, not having a period for some time, I decided to make a doctor's appointment. The menopause was at the back of my mind and so I took urine sample with me, as I remembered from a friend that this was how she was told the menopause had started. My GP is a good friend. He did the usual tests and asked me to go to waiting room while he tested the urine. When he called me back in, he had tears in his eyes. He said the words I never thought I would hear: "You are pregnant Lynda". I burst into tears but the bubble was burst slightly when he said: "but don't tell many people, as you probably won't carry it full term!" Well I did! To 38 weeks anyway, as I had to have an elective caesarean. The surgeon who performed it was also my obstetrician and he was delighted beyond words. My husband, daughter and all our families were just over the moon.

My stoma behaved perfectly during my pregnancy. It popped up slightly, but as it

was under my bump I could manage the changes. I was awake during the caesarean and the medical team were amazing. Obviously, trying to find an area to cut was a little tricky, but they managed it. I'm rather proud of the map of the world I now have on my tummy! Our son was the most beautiful baby, but did have to spend 11 days in neo-natal for a breathing problem. Being born at 38 weeks his lungs were a little immature. He is now a strapping 1.8m man of 30! We then went on to have another boy two years later. No special care for him, and another fine young man of 27!

Sadly, my repair broke down after the second pregnancy and I am too much of a wuss to go down the road of further surgery. I cannot pretend that the intimate side of our marriage isn't difficult because of this, but my husband is very understanding and we 'adapt'. Neither of us has ever looked back. The joy of having a family has far outweighed what I had to go through to get there. I couldn't breast feed, but that was more to do with my son being in neo natal than me having a stoma. And, having a stoma never got in the way of bringing up a young family. I would thoroughly recommend it and my message to any women reading this who are in a similar situation as I was all those years ago, is NEVER give up. As I write this, we are busy planning both of our sons' weddings! ■

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

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How many entries would you like each week?

How often do you want to pay?	<input type="checkbox"/> Monthly	£4.34 Direct Debit only	X =
	<input type="checkbox"/> Every 13 wks	£13	
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Your letters and e-mails

Ed's note: Jane R's letter on prescriptions and the new formularies (*Tidings* – summer 2019) struck a chord with many readers. Below are just a couple of the letters we received. As I explained on page 3 **Colostomy UK is aware that the changes are causing concern. On a separate matter, we were pleased to receive Sheila B's letter. As you probably know, our stoma-friendly toilet campaign is now in its third year. Sheila's letter re-states the importance of this work.**

Dear Sir/Madam

I would like to add my experience to those of Jane R in the recent edition of *Tidings*.

I too have had problems trying to obtain a prescription from my doctors for what as an ostomate you would consider quite a reasonable request. I have had my ileostomy for over 37 years, have moved house a number of times and until recently have not had any issues.

I have been with my current GP practice for four years, it is a very large practice and I have only once had an appointment with an actual GP. No one has asked me any questions about my ileostomy or about the supplies I need to live a normal daily life.

Recently they installed a new online system and at that time some of the items I use but not regularly, depending on output, condition of skin etc, have been removed from my re-order list. When I try to ask for an item to be added, I must justify why I want it to an assistant who does not even understand what an ileostomy is, and usually within earshot of the rest of the waiting room. On one occasion I was told the box of rings I requested and had used before, would probably not be approved as they were too expensive and an alternative would be issued. I insisted that this was not appropriate and if that was to happen, I would expect a call so we could discuss the matter. After a few days the prescription was issued but the item is still not on my re-order list.

Luckily, I always ask for items in advance as I know I am going to have this battle, or otherwise I too feel I would be making regular visits to the stoma care nurse or wound care clinic.

In your position as **Colostomy UK** are you able to take these concerns to a higher level to explain the needs of ostomates?

**Yours faithfully
Angela K**

Dear Tidings

I feel I must respond to the item by Jane R (*Tidings* Issue 54 Summer 2019) "...decisions of the CCG on stopping stoma items".

As a long term ostomate, with three bags stuck across my abdomen, I too have had what may be described as a run in with my local CCG. Way back in 2016 the powers that be decided to adjust the Joint Formulary regarding the supply of Stoma care products.

My initial experience was somewhat like that of Jane R, in that I was informed that I could only order this or that particular number of the product in question; this being discovered when my online order was not agreed between my GP and the Supplier, my GP having declined the amount ordered by me.

After investigation with the GP Practice Manager I contacted the appropriate person in the correct department of the CCG to explain my problem, this being the Pharmaceutical Advisor of the Medicines Management Team.

After explaining my problems to them I was asked to contact my Stoma Care Clinical Nurse Specialist in order to express my physical needs of several particular stoma care products and the quantities involved.

Having gone through the correct procedure all my problems were resolved following a meeting with my Stoma Nurse where I

stated the case for my ongoing ordering requirements. I came away with a list of products with agreed maximum monthly ordering amounts. I had to argue like Jane R for some products in order to preserve my skin, around in particular my enterocutaneous fistula, including adhesive remover spray and barrier wipes.

I agreed a set procedure with my online supplier that I would order on a specific date each month only those items that I required, never exceeding the quantity stated as the maximum amounts already agreed. Thus far I have NOT had any additional problems re continuing supplies of stoma care products.

So, my advice to anyone facing a cut down of their product needs is; firstly, ensure that you contact your Stoma Care Clinical Nurse Specialist, to explain what you need and why! Ideally have a numerical history record of what you have used in the past.

Secondly, every NHS/CCG Joint Formulary is different, but all contain the following statement in regard to Stoma Care Accessories: "There will be some patients on a named patient basis that will require products outside of the formulary to manage complex problems or sensitivity to product/s".

This statement allows you to argue for the specific item you require and provided that the Stoma Care Clinical Nurse Specialist agrees with your clinical need you will get it.

It would appear that some CCGs around the country have not explained their actions regarding the use of new Joint Formularies to the end user the Ostomate!

CONTINUED ON PAGE 33, COLUMN 1

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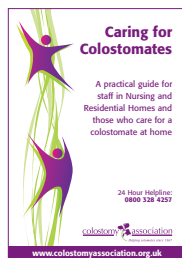
website:
ColostomyUK.org/information



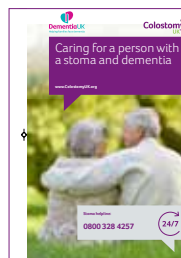
Active Ostomates Sport and Fitness after stoma surgery



Campaigns & Projects Flyer



Caring for Colostomates



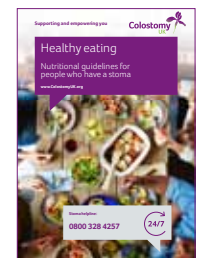
Caring for a person with a stoma and dementia



Colonoscopy through the stoma



Fundraising Pack



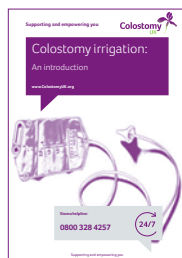
Healthy Eating



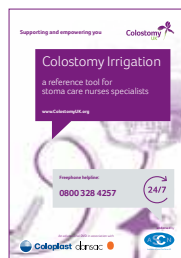
Helpline Cards



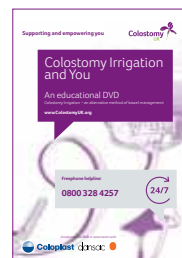
How will a Colostomy affect me?



Irrigation Booklet



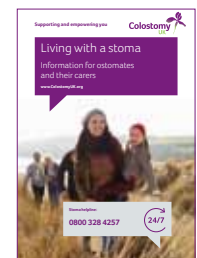
Irrigation DVD (nurses)



Irrigation DVD (patients)



Legacy Flyer



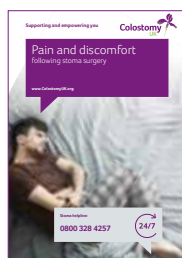
Living with a stoma



One to One (join us) Flyer



Ovarian Cancer and stomas



Pain & Discomfort



Parastomal Hernias



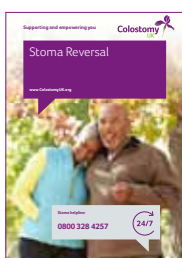
Rectal Discharge



Sam has a stoma (colouring book)



Stoma friendly toilet guideline and stickers



Stoma Reversal



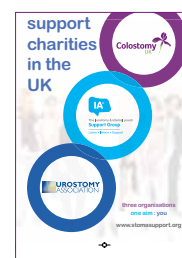
Tidings Magazine



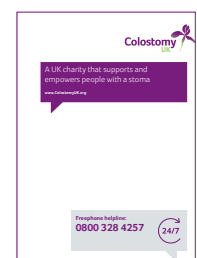
Travel Advice



Travel Certificate



Tri-Charity Leaflet



Welcome Pack

Your letters and e-mails

CONTINUED FROM PAGE 31 COLUMN 3

Jane R's comments such as: "...sometimes taken away without any thought or concern for anyone's feelings." are to be expected from patients who are kept in the dark and not informed of such radical changes to the accepted norm.

Lastly, I must express some concern upon reading that Jane R had an appointment with her GP only to discover "he had no knowledge of what exactly a stoma was or how it worked". I do wonder if the statement from my own (then) GP telling me: "you are your own expert as you know more about your complex needs as an ostomate than I ever will" has ever been heard by any other patients around the country.

It would seem to be that in order to be understood as an ostomate you have to speak to another fellow ostomate or a trained stoma care professional, or at a push perhaps read of a fellow reader or contributor to the *Tidings* magazine.

Robert H

Dear Tidings

On a recent visit to The Theatre Royal in Nottingham I was delighted to find that the disabled toilet was the best I have come across since receiving my colostomy.

I am always aware that I might need a change of pouch while out and about and so I have purchased a RADAR Key to have access to a disabled toilet and peace of mind. That peace of mind has been shattered time and again when I have emerged from using the toilet to face abuse from people waiting who assume that, because I don't have an obvious physical disability, I shouldn't be using the facility.

On the door of the facilities in the Theatre Royal there is a wonderful sign stating that not all disabilities are visible. How I wanted to shout Hurrah! Inside was even better – a large shelf for my stoma products, and that desperately needed hook behind the door!

I travel a great deal and I will look for such improvements to the disabled toilets from now on. The sign on the door is an enormous step forward in raising awareness of people with hidden disabilities and conditions.

For too long now we have had to explain ourselves. In certain public toilets, they are very basic and have no hooks, disposal bins or a shelf for us to use. So, a disabled toilet that displays this sign is a must and the addition of a shelf and hook make all the difference. It gives me confidence and reassurance when using them.

I am going to look out for the signs and where I don't see them, in hotels, supermarkets large department stores I am going to make myself a promise to write to the manager and point out how their facilities can be improved. I understand that it was a theatre goer that got the changes made to the toilets in Nottingham. So on behalf of us all I would like to say thank you to that person.

Sheila B

Please note:

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



We look forward to hearing from you, our readers:

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

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

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

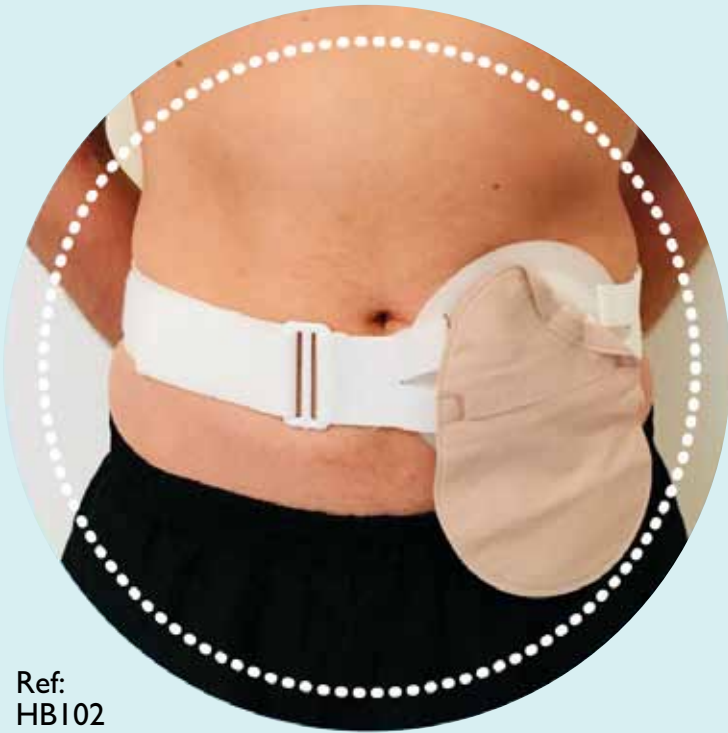


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SUPPORT



When people ask me what I do now that I'm retired and have stopped my involvement in local amateur dramatics they aren't always prepared for the answer. Telling them that I'm a hospital volunteer who visits stoma patients leads to some interesting conversations. Frequently people look a bit puzzled; many don't even know what a stoma is! For those who are unsure, I explain that I have had a stoma myself for 14 years and I go in to hospital to help patients adjust after their surgery.

The role of hospital visitor is one I find interesting as well as rewarding. My local hospital, the Royal Stoke University Hospital, has been encouraging volunteer patient involvement for over 20 years. Ernie Hulme, until recently a trustee of **Colostomy UK**, visited me on the ward when I had my APer surgery and gave me such encouragement that very soon afterwards I decided I too would like to be a visitor. A 'get-used to life with a stoma' period of a couple years was necessary first, before undergoing training with **Colostomy UK** (then the Colostomy Association) and shadowing another volunteer on a visit.

The bowel care team and consultants feel that volunteer visitors play a valuable part in the recovery of patients, amongst other things helping them to re-adjust to a new life after surgery. Those who are familiar with the history of **Colostomy UK** will know that our charity started in this way. Back in 1963, a surgical registrar at one of the London hospitals asked Gertrude Swithenbank (herself a colostomate) to visit his patients on the wards. [Ed's note: you can read the full story in *Tidings Summer 2017*.] It is comforting to know that more than 50 years on and the value of one ostomate talking to another remains just as important as ever. As a hospital visitor, I am following well-trodden ground!

The patients I see vary greatly. For those who are admitted as an emergency and wake up with a bag on their tummy, it comes as a huge shock (some initially think it is a dressing of some sort). Some are very frightened and in denial, not wanting to look at their stoma at all. For others the surgery is planned, but still an unwelcome solution to their illness. Even when the stoma is expected to be

Freephone: 0800 389 3111
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My role as a hospital visitor

Moira Hammond

only temporary, there are still many questions to be answered. Then there are others who, because their life has been restricted due to illnesses like Crohn's or colitis, have been expecting, if not begging, to have a stoma for years! Whatever the circumstances, in that immediate post-op period, people find it very reassuring to meet an ostomate – looking normal and enjoying their life.

My weekly routine starts with a visit to the stoma nurses' office, where they tell me which patients would like a volunteer to visit them and also what type of stoma the patient has. They do not give me much more personal information as this is confidential. I keep a stock of information at the hospital (including **Colostomy UK** literature), so I collect some introductory packs before going onto the wards. Most of the nurses on the wards know me well now, but I always make sure that somebody knows I am about to call on patients and I check that they are well enough for a visit. Sometimes I am advised against it at the moment; perhaps the patient has had a bad night, or is sickly.

Once I have found the patient I introduce myself and show them my hospital ID card, my **Colostomy UK** badge, and explain that I am a volunteer visitor who has a colostomy. There is often a look of surprise and disbelief (probably because I look so 'normal') and then, if they wish, we have a chat. I first confirm they are feeling well enough and on occasions arrange to come back another time, especially if they want me to meet their relatives/friends as well. It can be really useful to meet relatives because, as I'm sure readers will know from personal experience, there is a great deal to take on board in those early days after surgery. People's memories in hospital can be muddled, perhaps due to medication and shock, so another pair of 'ears' can really help. Relatives and friends often have questions too.

I give those I visit a pack of information from **Colostomy UK**. This includes a copy of *Tidings*, the booklet *Living with a stoma* and also the form to apply for a key to accessible toilets and an ID card. I make sure they know about the 24-hour stoma helpline, but emphasise that if it's medical advice that is needed, they must

contact their stoma care nurse or doctor. I reassure them about diet, giving them the relevant booklet if they want it. Sometimes people ask about holidays, so I make sure I have the *Travel advice* booklet to hand. People find it reassuring to know that I have made plenty of long-haul flights without any problems (no exploding bags!). I keep a reserve of other literature too, such as: *Active ostomates*; *Colostomy irrigation: an introduction*; *Stoma reversal*. I also tell them to take care not to strain themselves by doing anything too strenuous in the early days. Having heard so many ostomates say they wish they had been told this, I think it is sensible to broach the subject and warn about the issue of hernias, particularly when a patient seems overly keen to get back gardening or the golf course!

I also take the opportunity to tell patients about 'Outlook' our Staffordshire support group and the affiliated County Stoma Group if they live in the south of the county. Although support groups aren't for everyone, I feel it is important that patients I see leave hospital knowing how to connect with the local ostomate community. Our group has regular meetings attended by a stoma care nurse. We also hold an open day and have coffee mornings at a local pub. Our attendees, just like the patients I see on the wards, have different types of stomas. With this in mind, I make sure that I have literature from the Ileostomy Association and also the Urostomy Association on my hospital visits.

I'm not the only volunteer visitor. I work with three or four others, which is great because it means that between us we can make sure that most patients get to see someone. I am very passionate about my work for **Colostomy UK**. I am not sure how different my life would have been without my stoma but this, at-the-time unwanted 'gift', has given me a direction and focus which I am happy to make use of and, in doing so, hopefully help others. The work I do would not, however, be possible without the support I receive from all manner of sources: the nurses and consultants at the Royal Stoke University Hospital; **Colostomy UK**; the IA; the UA; and last, but not least, Ernie Hulme my mentor and inspiration. ■



Colostomy UK


Colostomy UK kit and merchandise

All profits raised from the following items help us to support and empower ostomates. Complete the order from below or order online at www.colostomyuk.bigcartel.com

Team Colostomy UK Beanie hat **£8.99**
Shipping £1.99

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

Qty required: _____




Team Colostomy UK Training singlet **£24.99**
Shipping £3.00

100% sublimated polyester features Team Colostomy UK logo on front and #ActiveOstomates on back

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

Qty required: Small _____ Medium _____
Large _____ XLarge _____



Colostomy UK Logo T-Shirt **£11.50**
Shipping £2.99

100% heavy duty cotton. Colostomy UK logo on front, Colostomy UK.org on back

Sizes available (inches): Small (34"/36"), Medium (38"/40"), Large (42"/44"), XLarge (46"/48"), XXLarge (50"/52")

Qty required: Small _____ Medium _____
Large _____ XLarge _____
XXLarge _____



Team Colostomy UK Training T-shirt **£29.99**
Shipping £3.00

100% sublimated polyester features Team Colostomy UK logo on front and #ActiveOstomates on back

Sizes available (inches): Small (34"/36"), Medium (38"/40"), Large (42"/44"), XLarge (46"/48"), XXLarge (50"/52")


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 RL hooded sweatshirt **£31.99**
Shipping £2.99

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

Team Colostomy UK RL hooded sweatshirt. Features printed logo on front and #ActiveOstomates on back

Sizes available (inches): Small (34"/36"), Medium (36"/38"), Large (42"/44"), XLarge (46"/48"), XX Large (50"/52")

Qty required: Small _____
Medium _____
Large _____
XX 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 as standard model plus:
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: _____

New products and services

Tidings is always interested to learn about new stoma care products and services from manufacturers and suppliers. If you have found a stoma care product or service beneficial to 'living with a colostomy' please let *Tidings* know. YOUR findings could make ALL the difference to others.



Salts Healthcare has some exciting news!




We are proud to launch our **NEW** monthly free Ostomy Podcast, **Me, My Bag and I**, available to download or subscribe to from your usual podcast provider. To find out more and get a step by step guide on podcasts visit www.salts.co.uk/podcasts

[See our main advert on page 18.](#)



NEW service from **medilink**

When English isn't your preferred language, it can sometimes be difficult to get the support you require for your stoma and/or continence care needs. That's why Medilink® has launched an innovative 3-way telephone translation service to help communicate and overcome this language barrier: the **NEW** Medilink® Language Support Service.



To find out more about the Medilink Language Support Service and how to sign up, visit:
www.saltsmedilink.co.uk/home-delivery/language-support

[See our main advert on page 18.](#)

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or visit : www.arelle.com

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+44 (0) 1924 9377 95

Life time Warranty

News from support groups across the UK

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

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

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

Shropshire BOTs (Bums on Tums) 8th Birthday Tea



40 of us enjoyed a delicious 8th birthday tea at The Orangery Restaurant again this year and were joined by the Mayor and Mayoress of Oswestry and Linda Gow and Karen Parker, stoma care nurses from Wrexham Maelor and Shrewsbury & Telford Hospitals.

We were delighted when the Mayor, Councillor John Price announced he has decided to make BOTs one of his chosen local groups to benefit from the Mayoral Fund. He told us: "I only found out about stomas about a month ago and I find it the most amazing thing. You say it is what it is, and just get on with it. I think what you have is amazing bravery and I think you have created a way of life for yourselves."

He is very keen to help us to raise the profile of stomas and we will be getting together in the near future to discuss ways of achieving this together.

I very much look forward to working with a Mayor who is showing such empathy toward ostomates.

Irene Constable
Shropshire BOTs (Bums on Tums)
Stoma Support Group

Outlook

The North Staffs Ostomy Support Group Annual Patients' day in Newcastle-under-Lyme.

An annual Patients' Open Day and Exhibition for all patients with a stoma resulting from bowel or bladder diversion surgery, will take place at Bradwell Lodge, Bradwell Lane, Porthill, Newcastle under Lyme, Staffs, ST5 8PS on Saturday 26 October from 11:30pm to 4:30pm.

It is anticipated that a member of the security staff from Manchester airport will be giving a talk and will also be available to answer individual queries.

Members of the Bowel Care Team from the Royal Stoke University Hospital and leading manufacturers will be present. All members and friends of ostomates are welcome to attend and light refreshments will be available.

For further details please contact Moira Hammond on **07788 402 195** or **07788 107 937**.

Cornwall Ostomy Support



Ken Jones reports that the group's Open Day in June went very well. Judging by the photographs Ken sent, it looks to have been a well-attended event!

For more information about the support group please contact Ken Jones on **01872 863 106** or e-mail: kenjones1808@gmail.com

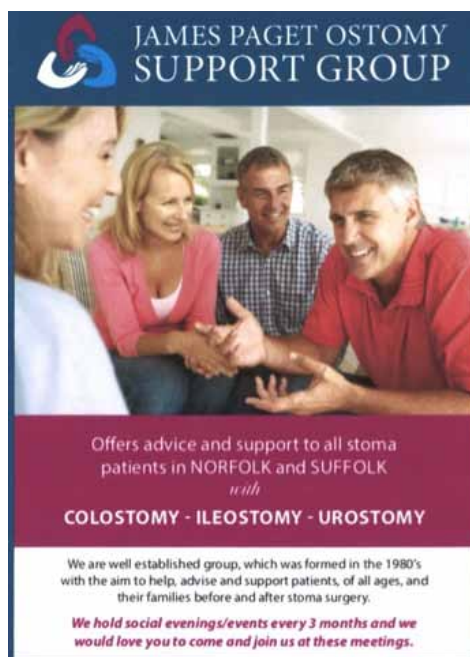
Mid Devon Ostomy Support Group

Janice Ford, who runs the group writes:

"I started the group in 2012. We have three or four meetings a year, attended by approximately 20-30 ostomates and their partners. We are a light hearted friendly group. We have a cup of tea or coffee and homemade cakes. In the past we have had talks from the Force Cancer Group, Blue Cross and an amputee mountaineer! We have quizzes too. We are also supported by the Exeter stoma department who give talks on various topics. Stoma reps also come along to show their products. We run a raffle with prizes that people bring and from the stoma companies, which covers the cost of the hall and refreshments. Our meeting in November has a Christmas theme."

For further details please contact Janice Ford **0792 397 5051** or **01884 799 369** email: janice234ford@gmail.com

James Paget Ostomy Support Group (JPOSG) for Norfolk and Suffolk Ostomists



A few years after we were formed we became a registered charity so that we could fund raise to help stoma patients that needed assistance. One of the things we did in those early days was to assist a young married couple to have IVF treatment. Having a family was proving impossible due to the amount of surgery the lady had undergone. The treatment was successful and they now have a son in his 20s!

Our present day project is to assist local stoma care nurses Helen and Lisa help a stoma care nurse in Nepal set up a service. Members of JPOSG are assisting with the cost of sending unwanted/unused stoma products out to her.

Our social evenings are held at Gorleston Golf Club. A light buffet and refreshments are available.

Membership to JPOSG is free with funds being raised by members giving donations towards the buffet and raffle and a book stall, which contributes towards room hire etc. We meet four times a year plus we have a fifth evening in November for our annual dinner. The group is well attended, with 50 plus people coming to meetings. Talks are given by healthcare professional and reps from stoma companies. Our stoma care nurses also come along, so professional advice is always available.

We would love you to come and join us, you can contact me Sandra Hutchings on **01502 585 955**, e-mail: **sandra.hutchings@sky.com**

Ed's note:

I was very pleased to receive the letter below from Barry McErlain (known as Mack). I think Mack must be one of few people to have run a stoma support group as a non-ostomate, only to become an ostomate himself years later!

Dear Editor

For many years I have assisted in the running of the Dewsbury and District Stoma Support Group, although I did not have a stoma, my wife did. I was a sort of associated member of the group. All this changed in early 2018 when I was diagnosed with bowel cancer, and it was thought best that I became a fully paid-up member of our group. The trouble was that nobody told me my initiation, from associate member to full member, would take five months and involve several visits to the hospital.

B McErlain

Having assisted with the group for many years, Mack has also been reflecting on why some support groups thrive while others seem to struggle. He conducted his own survey earlier in the year, which I thought readers would find interesting. This is an abridged version of his thoughts and findings:

Observations on Stoma Support Groups

In March of this year I emailed a number of stoma support groups with 10 questions

ranging from, how many members do you have in the group, what support, if any, do you receive from the local stoma care departments, to how often and at what time of day do you hold your meetings.

Thank you to all the groups that responded to my survey. Unfortunately, this was not as many as I had hoped, with just over 30% responding. With such a small number it is difficult to extrapolate strong meaningful results. However, a clear picture did emerge of why some groups are more successful than others.

Groups that are well-supported by stoma care nurses, be it in promoting the group to new ostomates, or attending group meetings on a regular basis, are very successful and attract an attendance of 40 to 50, some even reported a membership of over 100 in the early days. The groups that have little or no input from nursing staff are the ones that have a low attendance, in the 10 to 20 range, some with only five or six members, despite the fact that they show all the enthusiasm and drive of the larger groups.

As well as providing support to ostomates, the most successful groups have a variety of different speakers and a very full social calendar: BBQs, quizzes, trips to suppliers. They are all about living to the full and not letting the fact you have stoma be the end of all social activities. Another interesting

fact is the number of very successful groups that meet during the working day, afternoons or very early evenings being popular.

To stoma department staff, I say this: A little non-medical help from a person who has undergone surgery and understands what it is like to live with a stoma can be very beneficial. A 'shoulder to cry on', a caring word without any time restraints can work wonders. How many surgery appointments are taken up with patients seeking non-medical help? A well-supported and informed support group could free up more appointment spaces for the patients that really do need medical help. It is a win-win situation.

Mack

Member of the Dewsbury and District Stoma Support Group

Dewsbury and District Stoma Support Group

Meetings: Last Thursday of the month, (March to November), at 7:00pm

Venue: Oak Room, Oakwell Centre, Dewsbury District Hospital

For further details e-mail: **dews.ssg@gmx.com**

Colostomy UK: focus on fundraising



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

Thank you!

Why should you fundraise for Colostomy UK?

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

Get involved!

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



YOUR WILL, YOUR LEGACY



USING YOUR WILL TO HELP OSTOMATES OF TODAY AND TOMORROW

What will your legacy be?

You will have noticed that this edition of *Tidings* contains a copy of our brand new legacy leaflet. Legacy gifts both large and small have an extraordinary impact on the people we support.

You may remember reading earlier in the year about the legacy gift that was left to us by Isabel and Derek Jonas. Their gift has allowed us to better support ostomates in the North East of England. Legacies can be gifted to the charity to use as it sees fit, or to support a specific part of our work, such as our

24-hour stoma helpline, *Tidings* magazine, our Care workshops, or our Active Ostomates project.

The leaflet includes all the basic information you will need if you are thinking about leaving us a gift in your Will. If you have any questions please contact us at **fundraising@ColostomyUK.org** or call **0118 939 1537**. For legal advice you should contact a solicitor.

The number of people fundraising for Colostomy UK is growing every year and it's brilliant to see. But it does make it increasingly difficult for us to thank everyone personally through these pages! It goes without saying, that we are grateful to each and every one of you. Here are just a few of those who have been helping us to make a difference.

- ❖ The Chester stoma support group raised over **£500** from a group walk. Thanks also to Morrison's who match funded the amount raised.
- ❖ Martin Singleton raised over **£1,000** from having his hair cut!
- ❖ Chorley Panthers raised over **£1,000** from the raffle they held after our rugby league game in June.
- ❖ The South Coast Scramble club donated **£340** from their motorcycle scramble event.
- ❖ The team at CEVA Logistics took part in a 45km coastal walk from Herne Bay to Sandwich in Kent in September. The final amount raised has still to be counted but they're hoping to reach **£1,000**.
- ❖ Jack Tibbles walked 32km collecting litter as part of the National Citizens Service scheme and raised nearly **£100**.
- ❖ The Nikki Jay Academy of Dance chose **Colostomy UK** as the recipients of funds raised at their annual show in July, donating **£250**.

Good luck Christine!



Back in July, Christine Bradley completed the Peak District 100 kilometre event for Colostomy UK. If that's not enough, next April she'll be talking part in a sixteen day trek to Everest base camp!! Thank you.

We want your stamps!

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POSTAGE STAMPS

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



Send your stamps to -

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



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

Easy Fundraising



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

All you need to do is:

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

For more information or to register just visit

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

Grants and Trusts

Thanks to the following charitable trusts for their support of **Colostomy UK**: **The Colin & Anna Frizzell Charitable Trust**, **Joseph Strong Frazer Trust** and **The Tay Charitable Trust**.

Text giving



To donate £1, text
ColUK001 to 70201

To donate £5, text
ColUK001 to 70970

To donate £10, text
ColUK001 to 70191

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

We've recently launched a new Text Giving service. It's a quick and easy way to donate and help us to continue producing *Tidings*, our advice literature and all our projects and campaigns.

The amount you donate will be added to your mobile phone bill, or deducted from your pay as you go credit. You will receive a reply confirming your donation.

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

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

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

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

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

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

I would like to make a donation of:
 £20 £30 or whatever you are able to give £ _____
 I enclose a cheque or postal order made payable to **Colostomy UK**
 Please debit my Visa/Mastercard/Maestro Card with the amount specified

Card number _____ (Maestro only)
 Expiry date _____ Security code _____ (Maestro only) Start date _____ (Maestro only) Issue No. _____
 Signed _____ Date _____

giftaid it Thank you for your gift
 Thanks to the gift aid scheme – we can reclaim money on your donation from the government. For every pound you give us, we can claim an extra 25p. For example, a donation of £20 becomes £25 with gift aid, at no extra cost to you.
 I want to Gift Aid my donation and any donations I make in the future or have made in the past four years. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.
 Signature: _____ Date: ____ / ____ / 2019

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: _____
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 Account number: _____ Sort code: _____

I would like to make a **regular donation*** of £20 £30 or other amount (please state) £ _____
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 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: ____ / ____ / 2019

T55

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



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

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.

Stoma Care Open Day Lincolnshire

Healing Manor Hotel,
Stallingborough Road, Healing,
North East Lincolnshire, DN33 2BA
1 October 2019
Contact: louise.walton@dansac.com

Coloplast Event London
Penfold Community Room, Penfold Court,
60 Penfold Street, Marlyebone, London,
NW8 8PJ
1 October 2019 10:00am–4:00pm
Contact: Sam Fenton on gbsfe@coloplast.com or 07721 261 654

Whiston Hospital Open Day

St Annes Millenium Centre, View Road,
Rainhill, Prescot, Merseyside, L35 0LE
3 October 2019 1:00pm–4:00pm
call 01522 512 512 and ask for stoma care

Shropshire B.O.T.S. (Bums on Tums) 2019 Open Day

The Memorial Hall, Smithfield Street,
Owstrey, SY11 2EG
3 October 2019 10:30am–03:00pm
Irene Constable 01691 238 357
ireneconstable@phonecoop.coop

Coloplast Event London

Bishop Crighton House, 378 Lillie Road,
London, SW6 7PH
4 October 2019
Contact: Sam Fenton on 07721 261 654
or gbsfe@coloplast.com

Stoma Care Open Day

Wanstead & Snaresbrook Cricket Club,
London, E11 2LW
5 October 2019 1:00pm–3:30pm
Whipps Cross University Hospital Stoma
Team: 020 8535 6563

Addenbrooks Hospital Patient Open Day

Addenbrooks Hospital, Frank Lee Centre
5 October 2019 10:30am–2:30pm
Contact: Stoma Care Team

Sheffield Annual Stoma Care Open Day

Hillsborough Arena, Middlewood Road,
Sheffield, S6 4HA
8 October 2019 11:00am–3:00pm
Northern General Hospital: 0114 226 9156

Coloplast Event Stockport

Alma Lodge Hotel, Buxton Road,
Stockport, SK2 6EL
15 October 2019 1:00pm–4:30pm
Contact: Coloplast: 0800 220 622

Arrowe Park Hospital Stoma Care Open Day

Floral Pavillion Theatre,
Marine Promenade, New Brighton,
Wirral, CH45 2JS
16 October 2019 10:00am–2:00pm
0151 678 5111

Wolverhampton NHS Trust Stoma Care Open Day

Grand Central Hotel, Sun Street,
Wolverhampton, West Midlands,
WV10 0BF
23 October 2019 10:30am–3:30pm
Contact: Stoma Care 01902 307 999

Barnsley Hospital Stoma Care Open Day

Fairway Hotel, Dodworth, Barnsley,
South Yorkshire, S75 4LS
24 October 2019
Stoma Care: 01226 432 528

Annual Patients Open Day & Exhibition 2019

Bradwell Lodge, Bradwell Lane,
Porthill, Newcastle Under Lyme,
Staffordshire, ST5 8PS
26 October 2019 11:30am–4:30pm
Contact: Moira Hammond
07788 107 937 or 07788 402 195

North Devon Stoma Care Open Day
The Barnstaple Hotel, Braunton Road,
Barnstaple, Devon, EX31 1LE
7 November 2019 10:00am–1:00pm
Contact: Caz Smith 01271 322 464

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

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

National support organisations

IA The Ileostomy and Internal Pouch Support Group

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

UA Urostomy Association

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

Mitrofanoff Support

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

IOA International Ostomy Association

www.ostomyinternational.org

Junior Ostomy Support Helpline (JOSH)

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

Breakaway Foundation

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

Bowel Cancer UK

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

Macmillan Cancer Support

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

Crohn's and Colitis UK

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

The IBS Network

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

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

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

Stoma support groups in your county

Channel Islands

Guernsey

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

Jersey

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

England

Berkshire

E.B.O.C (East Berkshire Ostomy Club)
Jackie Dudley: 01344 426 652
Reading Bowel Cancer Support Group
Ted Wingrove 0118 961 8297 or
07974 790 558
WAMS (Windsor, Ascot, Maidenhead &
Slough) Stoma Support Group
If you are interested in joining then
please e-mail Giovanni:
info@ColostomyUK.org or
call on 0118 939 1537

Bristol

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

Buckinghamshire

High Wycombe Stoma Support Group
Telephone 0800 318965
Milton Keynes Stoma Support Group
(MKSSG)
Morag Harvey (Secretary)
mkssg.sec@gmail.com 07843 768 386
You Are Not Alone Stoma Support
Group
Carla 07846 354 918
e-mail: carla_wright@sky.com

Cambridgeshire

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

Cheshire

Countess of Chester Hospital Stoma
Support Group
Stoma Nurses 01244 366 170
East Cheshire Stoma Support Group
Catherine McIntosh: 01477 535 071
Stockport Support Group
Marion Caulfield: 0161 320 9400/
0800 652 6667
Warrington Ostomy Support Group
Louise or Joan on 01925 454 813

Cleveland

Ops 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: trebornosivad@tiscali.co.uk
Darlington Support Group
Margaret Clothier, Tel: 0191 333 2184
Durham Stoma Support Group
Lynn Ridley Tel: 0191 333 2184

Cornwall

Cornwall & Plymouth Bowel Cancer
Support Group
The Secretary: 01872 241 145,
cbcsginfo@gmail.com or
www.cornwall-bowel-cancer-support-group.co.uk
Cornwall Ostomy Support
Ken Jones: 01872 863 106 or
www.cornwallostomysupport.org.uk
Lanhydrock Ostomist Group
Mandy Rowe: 01726 832 642
murphy.rowe781@btopenworld.com;
Henry Kendall: 01208 850 986
h.kendall380@btinternet.com

Cumbria

Grange Cancer Support Drop in
Marie O'Connor 01539 533 279
Stoma Support Groups in North
Cumbria
Stoma Care Nurses 01228 814 179

Derbyshire

Diverted Local Stoma Support Group
Diana Manning: 01283 541 311

F.I.S.H.Y.S. (Friendship, Information,
Support & Help for Young Ostomates
(age 18-45)
Email for more details:
fishysderbyshire@gmail.com

Devon

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

Dorset

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

Essex

Connect
Lin Hart 01279 505 273
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
stepsexessex@gmail.com

Hampshire

Replummed stoma support group
www.replummed.me

Solent Ostomates Support Group (S.O.S.)
For information tel. 07527 707 069 or solentostomates@hotmail.co.uk

Southern Ostomy Group
Caroline or Karen on: 07756 819 291 southernostomygroup@hotmail.com
The Hampshire Ostomates Support Group
Contact Nicki Beare on 07771 558 458 or Nichola0405@yahoo.co.uk

Waterside Stoma Support Group
Hazel Derham: 023 8089 1934 or hayjuder@sky.com

Wessex Urology Support Group
Mrs Jo Stacey: 07910 786 978

Herefordshire

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

Hertfordshire

Ostofriends Support Group
Peter Lannen ostofriends@gmail.com 07501 137 511

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

Isle of Wight

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

Kent

Ashford Stoma Support Group
Carole Hobbs: 01303 814 014

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

Dartford Ostomy Group Support (DOGS)

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

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

GOGS (Gravesend Ostomy Support Group)

Tracey: 07779 155 846 or Helen: 07710 780 958

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

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

Maidstone Stoma Support Group
Judy/Kirsty: 01622 224 305

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

Sheppey Ostomy Group Support (SOGS)

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

SWANS Stoma Support Group - Swanley

Heather - 07711 445 312 heather601@virginmedia.com

Thanet Stoma Buddies Support Group
Kathy 01843 291 825

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 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 crc-stomanurses@bfwhospitals.nhs.uk

Leicestershire

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

Lincolnshire

Friends East Coast Support Group
Betty Williams - 01205 724 120, Sheila - 01205 364 493

Grantham Support Group
Bobbie/Rachel: 01476 464 822

London

Bowel & other Cancer Support Newham
020 8553 5366

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

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

Newham Stoma support group
Contact Lauren King 020 7055 5576

Merseyside

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

Bowel Cancer and Stoma Support Group (BeCauSe Group)
For further details please ring 07948 120 955

St Helens Cancer Support Group
Denys Floyd- 01744 884 097

Middlesex

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

Norfolk

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 Minshall: 07714 479 320

Hexham Ostomy Group
Judith on 07967 927 286

Northumberland Cancer Support members@northumberlandcancersupportgroup.co.uk

Nottinghamshire

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

Nottingham QMC Stoma Support Group
Rosemary Brierley: 0115 982 6691

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

Shropshire

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

Somerset

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

Staffordshire

Outlook The North Staffs Ostomy Support Group
Moira Hammond 07788 402 195 or cm.hammond@ntlworld.com
County Stoma Group
Christine Bryden 07757 911 726 or countystoma@yahoo.com

Norfolk

James Paget Ostomy Support Group
Sandra Hutchings: 01502 585 955

Suffolk

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

James Paget Ostomy Support Group
Sandra Hutchings: 0150 258 5955

Surrey

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

SUPPORT

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

Stoma Support Group
Robin Young: 01428 723 255

Sussex

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

Tyne and Wear

Gateshead Stoma Patient and Carer Support Group
Stoma Care Nurses: 0191 445 3152 or
email stuart.sutcliffe81@yahoo.com
NHS Molineux Support Group
John Burchell 0191 265 1047
Royal Victoria Infirmary Support Group
Stoma care nurse specialist:
0191 282 4116
Sunderland Support Group
Michele Downey 07704 949 30
micheledowney@outlook.com

Warwickshire

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

West Midlands

Coventry Stoma Support
Martin - 07947 385 643

Wiltshire

Swindon IA
www.swindon-ia.org.uk
Wessex Stoma Support Group
Karen Berryman 01980 590 599
or on wessex.stoma@yahoo.co.uk,
www.wessex-stoma.co.uk

Worcestershire

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

Yorkshire

Acorn Ostomy Support Group
07580 693 155 (After 6:00pm)
Airedale Stoma Support
Sue Hall: 01535 646 373
Barnsley Bottoms Up Stoma Support Group
Stoma Nurses 01226 4325 28 or
Celia Utley (Chairman) 01226 284 262
Behind You (Calderdale & Huddersfield Bowel Cancer Support Group)
Stoma Care Nurses: 01484 355 062
Bottoms Up (for urology and colorectal cancer patients)
John Whelpton 07974 657 146 email:
midyorks.bottomsup@gmail.com
Bradford Stoma Support Group
Please get in touch with Lisa Hall on
07552 276 747

Dewsbury & District Stoma Support Group
June 07884 003 945 or
dews.ssg@gmx.com

Hambleton and Richmondshire Ostomy Support Group
Stoma Care Nurses - Judith Smith and
Mary Hugil 01609 764 620/
07736 295 131

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

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

Scarborough Stoma Support Group
Stoma Care Team: 01723 342 388

The Hull and East Riding Colostomy Support Group
Pete Smith: 07989 565 335 or
Pete Rennard: 07939 518 642/
01482 793 966 or Rosanna Grimsby:
01482 801 575. www.hercosg.org.uk

Northern Ireland

County Antrim

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

Republic Of Ireland

County Mayo

Mayo Stoma Support
Marion Martyn: +353 94 902 1733

Dublin

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

Scotland

Ayrshire

Ayrshire & Arran Stoma Support Group
Jim Krasewitz: 07729 771 350 or
Susan Latimer 07790 929 268
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

Aberystwyth

West Wales Stoma Support Group
Shirley Jones:
shirleyjones78@gmail.com

Bridgend

Bridgend Ostomy Patients Support Group
Anita Brankley (Secretary)
01656 645 602 or
bridgend.ostomy@gmail.com

Carmarthenshire

W.O.W.S. Wales Ostomy West Support
Judi Hopkins 01267 237 847 or
Julian Boswell 01554 772 877

Conwy

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

Gwent

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

Mid Glamorgan

C.A.S.S Colorectal and Stoma Support Group
Chair person 01685 877 144

Pembrokeshire

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

Powys

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

Rhondda Cynon Taf

Royal Glamorgan Stoma Care Support Group
Domenica Lear 01443 443 053

Swansea

Swansea Ostomy Self Help Group
Glynis Jenkins: 01792 418 245

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