

Spring 2022 | Issue 65

Colostomy
UK 

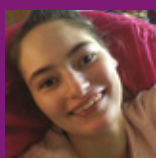
Tidings

AWARD-WINNING

Supporting & empowering ostomates



Introducing
Stoma Squad



SIAN COOK
Amy's Story



RICHARD BIDDLE
Dealing With
Life's Curveballs

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Real people**

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Dear readers

A belated happy New Year to you all. I hope everyone had an enjoyable Christmas. Thankfully mine resembled something close to normal compared to the previous year, when being in Tier 4 meant the day was a write-off. In fact, it was rather a special day in the Biddle household, as we got to spend it with our new grandson, Henry (three months old). The only downside was that our daughter, who is a paramedic, had to work.

It was a very hectic start to the year at Colostomy UK, as we moved premises in late January. Some would say that packing-up and moving, while putting together this edition of Tidings and trying to adhere to government working from home guidelines, made the beginning of 2022 exciting. Personally, I would call it stressful! You can find out more in Colostomy UK News (pages 6 & 7), including our new address. Please be sure to use this if you are writing or sending us something!

With summer holidays looking more likely to happen than in the last few years, we have an update for you on our work with airports, which will hopefully prove useful. This is complemented by a short piece from Mervin, one of our volunteers, who has travelled extensively since his surgery.



You'll see that he has some good advice for the less experienced. If you have the practical aspects of travel as an ostomate sorted, then you can just enjoy the photos of some of the exotic destinations he's been lucky enough to visit!

Our real lives stories are all very different. Tom Byrne has some valuable advice, especially for new ostomates. Tuppy Hill talks about how she overcame the practical and psychological barriers to swimming as an ostomate and the positive effect this has had on her physical and mental wellbeing. Sian Cook speaks as a mother and describes the trials she and her family have faced caring for their daughter, who has recently had stoma surgery. Finally, in Dianne's story we hear about how her holiday in Scotland last year was interrupted by having an emergency Hartmann's procedure and how she has subsequently adapted to life as an ostomate who lives in a motorhome.

Unfortunately, we don't have the usual Dear Nurse feature. Pressure on the NHS has been such that it wasn't possible to find a healthcare professional who could write something in time. But the good news is that we should (touch wood) have two in the summer, one of which will look at having a colonoscopy through the stoma, the other at safe exercise after surgery. The common denominator in our final two articles is the issue of spreading stoma awareness to people in general. The first looks at the work of the 'Stoma Squad' who feature on our front cover. The second is an update on the Colostomy UK Rugby League team, in which Giovanni outlines just how many people have been reached through the reporting of the team's exploits on social media and in the printed press.

Richard

Richard Biddle
Editor, Writer & Researcher



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Colostomy UK is a national charity that offers support and advice to people living with a stoma, their families, carers, and friends. We're here if you have questions, need support or just want to talk to someone who lives with a stoma.

We also run projects to **EMPOWER** ostomates to return to sports, hobbies and other interests and give them the confidence to take up fresh challenges. We are advocates for ostomates' rights and their voice on the bigger issues. Our campaigns raise awareness and encourage organisations to make their facilities more inclusive. **SUPPORTING** and enhancing ostomates' wellbeing is at the core of everything we do.

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 call 0118 939 1537
info@ColostomyUK.org

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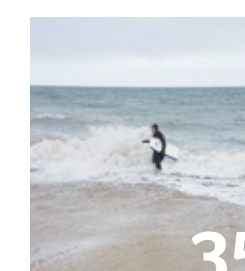
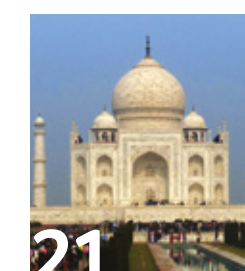
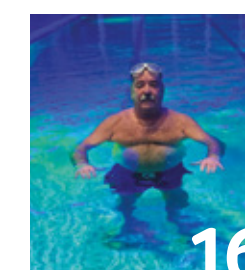
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Join our 'private' support group today simply put 'Colostomy UK Support Group' into your Facebook search bar, click on 'Group' and click on 'Ask to join' you will be assured of a warm welcome!



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Donating to Colostomy UK

An annual donation of £25 (or what you can afford) allows us to produce Tidings and to continue our vital work, supporting, and empowering ostomates – see page 9 for our donation form.

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



Colostomy UK news



Libby Herbert
General Manager
Libby.Herbert@ColostomyUK.org



We Have Moved!

In January we said goodbye to Enterprise House, which has been Colostomy UK's home since 2013, and moved to Winnersh.

For those unfamiliar with Berkshire, Winnersh lies just outside of Reading. Our new offices are modern, smaller, safer, and, with their out-of-town location, cheaper too! Importantly, they have good road and rail links, making them very accessible. Please note our new address* and start using it with immediate effect:

Colostomy UK
100 Berkshire Place
Winnersh
Wokingham
Berkshire
RG41 5RD

Our phone numbers and e-mail addresses are unchanged.

* We have mail redirect until mid-July, so don't worry if you have recently sent something to our old address!

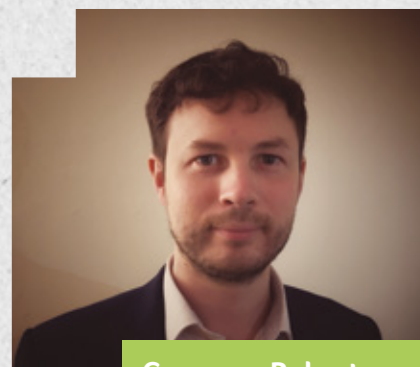
We Welcome Some New Members to the Team

In recent editions of Tidings we have advertised a number of job vacancies. We are glad to report that some of these have now been filled.

On page 33 you can meet Maxyne, our new Volunteers & Community Manager. Here we are pleased to introduce Margi Pandya, our new Support & Finance Co-ordinator, and Cameron (Cam) Robertson, our new Public Relations & Engagement Manager.

Margi joined the team in mid-January and shares her role with Angela (who callers to our helpline may have spoken with). Born in India, Margi worked as a teacher in both her native country and Singapore, before moving to the UK in 2019. As any good teacher should, she has devoted her life to acquiring knowledge and is passionate about using her skills and experience to help others. In her spare time, Margi enjoys arts and crafts activities and reading, especially biographies. She also likes to keep her husband in order... with a Masters' degree in Commerce, she keeps tabs on his spending, while the teacher in her encourages(!) him to keep active and keep learning... her favourite command when she thinks he is slacking, is to tell him to 'upgrade yourself!'

Cam joined us a few weeks after Margi and so escaped all the upheaval of our move to Winnersh! Supporting those in need and groups of people who face challenges living life to the fullest, has



Cameron Robertson



Margi Pandya

been the focus of his previous roles, making him ideally suited to working for Colostomy UK. He also has a good deal of experience in digital marketing, which makes him a key addition to our team. When he isn't spending time with his young family, Cam's pursuits include meditation and doing all he can to avoid going to the gym. He's also a bit of a deep thinker (or so he tells us!) and enjoys playing strategic board games.

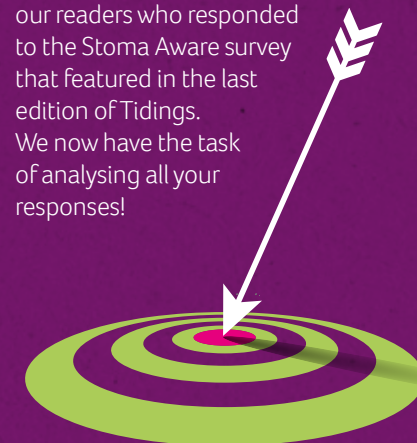


Strategic Update

In the summer 2021 edition of Tidings we announced that our application to work with Pilotlight, an organisation that brings businesses and charities together to support strategic planning, had been accepted.

Since then, we have been working hard behind the scenes to develop our aims. Most recently, this included getting together a group of our volunteers and ambassadors so that they could give their input to the overarching purpose and vision we are developing for the charity. The next stage will be the development of our business plans, key objectives and working out what our priorities are.

We also wanted to take the opportunity of thanking all our readers who responded to the Stoma Aware survey that featured in the last edition of Tidings. We now have the task of analysing all your responses!



There are Still Opportunities to Join Our Team

Finance & Operations Manager

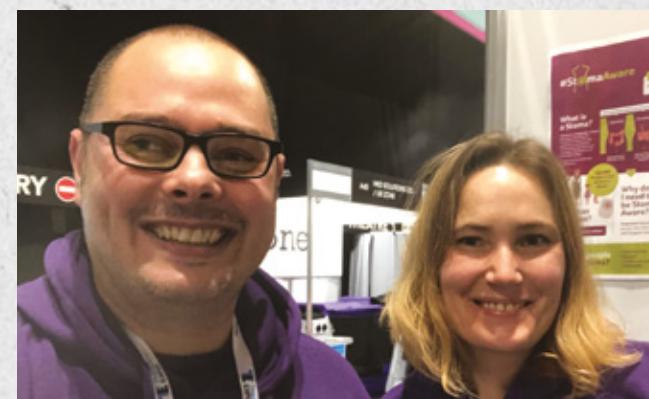
We are looking for someone to head up Finance and Operations for our charity. This will be a demanding and wide-ranging role, covering support services, IT, database, recruitment, system improvements and financial management. Working closely with the CEO, Finance Trustee and Management Committee, the job holder will be responsible for the overall financial management of Colostomy UK and so will need to be a qualified or part-qualified accountant. As Operations Manager they will also oversee the day-to-day operations of the office and its support services. This includes managing a small team.

Secretary & Governance Trustee

David Buchan Colostomy UK's current Secretary & Governance Trustee will be stepping down after our Annual General Meeting in June this year, when the position will become vacant.

The overall role of the secretary is to ensure that Colostomy UK complies with the requirements of company law. If you have strong organisational skills, are proficient in running meetings, and competent with office IT applications, then this unpaid, voluntary role could be just what you are looking for. It's a great opportunity to get involved with the running of Colostomy UK and to make a difference to lives of people who have stomas.

For more information on either position contact: Libby.herbert@colostomyuk.org



Occupational Therapy Show – Birmingham

In November last year, Giovanni Cinque (Fundraising & Campaigns Manager), Angela Jarvis (Support & Finance Co-ordinator) and Andrew Bird (our new Clinical Trustee) represented Colostomy UK at The Occupational Therapy Show at the NEC in Birmingham. Held annually and the biggest show of its kind in the UK, the event proved very worthwhile. It was a great opportunity to bring the work of Colostomy UK to allied health professionals across the country. Thank you to Coloplast for sponsoring our attendance.



Dear Reader,

I've had a stoma since January 2001. I went to hospital for a hysterectomy only for it to be discovered I had bowel cancer. I didn't find out until after I awoke from surgery. It was then too that I was told the news: 'You have a colostomy'.

It was obvious to the nurse that I had no idea what a colostomy was. I'll never forget what she said: 'Jackie, you have a bag on your tum.' Little did I know what this entailed. My stoma saved my life but took time to get used to. I needed lots of help and support in those early days.

Returning to the room later my husband and I listened as the surgeon explained how the cancer had attached itself to the bowel, making it necessary to remove part of my intestines and form a stoma. I was told that this could not be reversed.

Later that year I attended a coffee morning at my local hospital where I met a volunteer from Colostomy UK. It was the first time I had ever met anyone else with a stoma. That day has stayed with me forever. I was introduced to Tidings magazine – full of supportive articles, advice and hints and tips, and of course all the other support services Colostomy UK offer, including their helpline.

Being able to talk to people who knew what I was going through was, quite simply, life changing.

That was two decades ago. I am now a volunteer for Colostomy UK. Giving back in this way is so important to me. After every call I take on the helpline I think back to that coffee morning all those years ago and hope that I too, have made life just a little bit easier for a fellow ostomate.

I hope that you are able to make a donation to Colostomy UK and help to make sure that anyone affected by stoma surgery gets the information and support they need, just like I did all those years ago.

Best Wishes



Jackie Dudley

Jackie Dudley

Supporting & empowering ostomates
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By post – using the form opposite

FREEPHONE STOMA HELPLINE: 0800 328 4257

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Your donation to Colostomy UK will make a real difference and help us to better support more ostomates like you. Please consider supporting us by donating, or setting up a regular standing order or direct debit (see reverse page). Thank you.

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- You can cancel a Direct Debit at any time by writing to your Bank or Building Society. Written confirmation may be required. Please also send a copy of your letter to us.



Amy's Story

BY SIAN COOK

Our beautiful daughter Amy was born with multiple health problems. The prognosis wasn't great.

We were told that Amy was unlikely to live beyond her teens and her care needs would be great. She would be unable to sit up, walk or talk and would be totally dependent on care givers for all her needs. But Amy continues to defy the odds. Although she has (and continues) to endure much, she is now 24 years old.

Amy's story, and the stories of others like her, need to be told. It is something I feel very passionate about. If they aren't, then families in similar situations are going to continue to feel isolated. Until more people become aware of the positive impact a colostomy can have on a person's life and the lives of those around them, stomas will continue

to be seen in the wrong light. If we don't tell the stories, then people will never properly understand the difference that charities can make and why it is so vital that they receive our support, even when times are hard.

Amy's initial diagnosis was microcephaly. This is a rare condition in which the baby's head is much smaller than it should be. Often the child also has a small brain and thus an intellectual disability. Within months of Amy's birth, our lives began to revolve around visits to paediatricians, neurological paediatricians, physiotherapists, speech and language therapists, and dietitians, along with orthotics and wheelchair services. The toll this took

was considerable and went far beyond practical things like recalibrating our daily routine to accommodate the appointments. We struggled emotionally too. With my husband frequently away with work, Amy's older sister often had to accompany us to the hospital.

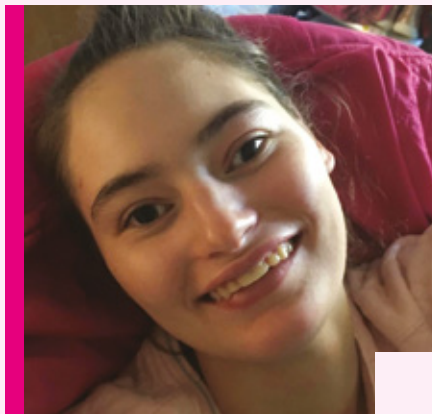
This was distressing for everyone and tough on her particularly, as she had no choice but to see and hear things that no child should. Matters did not improve when at age two Amy started to have epileptic seizures, leading to many frightening episodes over the next few years as she was blue lighted to hospital.



It was after this period that Amy's bowels became a problem. As things deteriorated, we were referred to a gastroenterologist at our regional hospital, who diagnosed bowel dysmotility. This is where the gut does not work properly when moving things through the system. As well as experiencing bouts of diarrhoea, Amy suffered from vomiting and constipation. For the next couple of years, medication was prescribed, but without good effect. Amy's symptoms had a hugely detrimental effect on her life. The absorbent pads she wore couldn't contain the liquid faeces and so she spent much of her school day in the bathroom being showered and put in clean clothes. Amy was often in discomfort and the teaching staff worried she was not interacting. Outside of school, many a time we were forced to change and cleanse Amy as best we could on toilet or vehicle floors, due to the general lack of Changing Places toilets (toilets with a hoist and height adjustable table).

When Amy reached 16, it was concluded that there was little chance of things improving as she was now fully grown. Two treatment options were suggested: a Peristeen washout or a colostomy. The former wasn't realistic with Amy's disabilities. The latter though seemed very radical and prompted much research on our part. A Best Interest Meeting was held, at which it was agreed to proceed with the surgery. For those who don't know, this is a multidisciplinary meeting (including family, healthcare professionals, social workers, etc.) arranged to make a specific decision about an adult's care/treatment, when the patient is deemed not to have the mental capacity to make the decision themselves.

A sense of relief followed, although many practical challenges still lay ahead. As Amy was considered an adult, she had to go on an adult ward. Parents are not allowed to stay on adult wards but as the staff were unable to provide all the care Amy required, I was allowed to stay. Amy also couldn't sleep safely in a hospital



bed, so we had to take in her portable bed with its own mattress (which we always do for hospital stays – no mean feat!). Prior to the operation, the surgeon marked where her stoma would be located. After she left, I realised this would place it right under the waist belt of Amy's wheelchair. It therefore had to be repositioned, resulting in the intestines being pulled across to form a right-sided end sigmoid colostomy.



There is no doubt that having a colostomy has improved Amy's quality of life, although we had some hurdles to get over before this became clear. Following the operation, the surgeon said Amy no longer needed her laxative medications. But a month later, while we were on holiday, she became inconsolable with pain. The emergency doctor concluded that Amy was severely constipated and that her senna and sodium picosulfate should not have been stopped. From a medical perspective, Amy is a complex case and so the impact of changing medications is not always realised immediately. Thankfully, after much adjustment, we reached doses that worked for her.

Other difficulties related more directly to stoma management. We struggled at first to find the right bag for Amy. In the end we used half-moon adhesives which helped with bag security, but not before having to cope with lots of accidents. The bags Amy uses now are much better. We also discovered very quickly how challenging it is emptying or changing Amy's bag while she is in her wheelchair. This is made more difficult by the fact that Amy has strong involuntary movements. Ideally, changes need to be done with Amy on a changing table with at least two people, but this is often impossible, especially when we are out and about. Although there are now more Changing Places facilities, they are still few and far between. We have become very adept over the years! The issue of bag changing, and stoma care more generally, is one that we continue to wrestle with. Every time someone involved in her care moves on, so fresh training is required for their replacement.

As Amy and the rest of us adapted to life with her stoma, I became ever more convinced that her health issues were in some way genetic. Finally in 2015, after much pushing, we had an appointment with a genetics consultant who diagnosed Amy with a rare genetic condition called FOXG1, a congenital variant of Rett Syndrome (which affects brain

development and results in severe physical and mental disability). At the time, there were only a handful of cases in the UK. A Professor based in Cardiff, who is a leading light on the condition, allowed me to take Amy to see him. It transpired that bowel dysmotility is one of the common symptoms experienced by people with FOXG1. Getting the diagnosis was something of a watershed moment. It explained so much and as a family we felt a sense of relief knowing that Amy's bowel problems and other symptoms (such as her strong involuntary movements) were due to her condition. This diagnosis has been invaluable ever since, particularly when seeing healthcare professionals.

Sadly, Amy's state of health has continued to become more complex over time. A couple of years ago when Amy was at home (she now lives in a specialist nursing home for young people and comes home regularly) I noticed blood in her stoma bag. Following a referral to a gastroenterologist a colonoscopy was arranged. Due to Amy's disabilities, it was done under general anaesthetic. This and the subsequent biopsy confirmed that she had Crohn's Disease. Fortunately, it wasn't severe but nevertheless, the symptoms were causing her significant pain. Amy also has worsening scoliosis and reflux oesophagitis, so knowing the cause(s) of her pain episodes can be very hard. This is all the more distressing for us as a family, because of her inability to communicate. We can tell when she is in pain, but by this point we know she will be in immense pain, as a high pain threshold is a characteristic of FOXG1.

Sometime after Amy's Crohn's diagnosis, she started to suffer from rectal bleeding. Tests showed her calprotectin levels were high and further investigation revealed she had a mucus plug which had built up over the years since she had had her colostomy. I now know that mucus can be a problem for people who have stoma surgery. However,



the usual options for addressing it were not possible for Amy, so she was prescribed daily enemas. This process took some weeks and caused Amy considerable discomfort before she could get rid of the mucus. Further flares with proctitis have necessitated Amy having courses of prednisolone steroids with good effect.

I started Amy's story by talking about the difference that charities can make to people's lives. I want to finish on this point. As we tried to cope with Amy's rectal bleeding and mucus build-up, I was starting to feel completely overwhelmed. It was becoming more and more difficult to manage Amy's health. It was then that I came across

Colostomy UK. It was like a breath of fresh air talking to people who cared and wanted to help. After explaining our situation, I was put in touch with a volunteer. She was incredibly helpful as her experience enabled her to explain things very clearly. She emphasised the importance of keeping mucus plugs at bay by inserting glycerine suppositories on a regular basis as she, like Amy, was unable to expel mucus as most can. This advice has made such a difference to the quality of Amy's life. Touch wood, all is good with Amy's colostomy and related conditions now. Hopefully this will continue!





The fit is
the difference
between staying in
and going out

Walton, SenSura® Mio Concave user



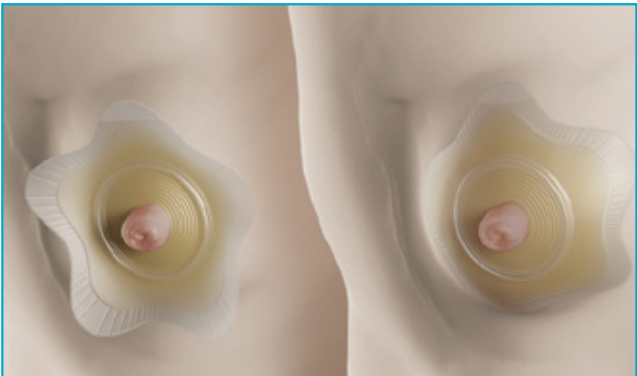
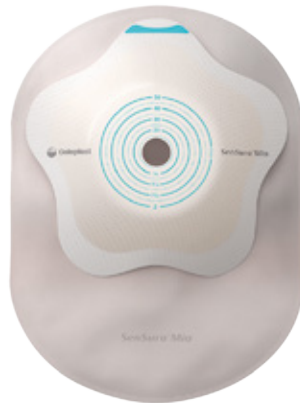
“My body changed, but my stoma bag didn’t. That’s why it didn’t work as well anymore.”

It can be difficult to find a baseplate to fit over curved body areas around the stoma without getting creases and folds. The **SenSura® Mio Concave** has a star-shaped baseplate that is specifically designed to grip the curved area for a snug and secure fit - even when bending and stretching.

Walton first experienced **leakage** soon after getting his stoma. After surgery, his body shape changed and the stoma baseplate he was using no longer had a **secure fit**. After trying the **SenSura Mio Concave** - designed specifically for curved body profiles – Walton now enjoys peace of mind.



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

Control Your Stoma, Don't Let it Control You

BY TOM BYRNE



I had stoma surgery back in 2008 as a result of bowel cancer. At the start, the thing I struggled with most was no longer having any control over when I 'went'.

It took time for me to get used to the new sensations I felt in my body and, as I adjusted, my self-confidence took a knock. Very quickly, my stoma seemed to control my life. I felt very anxious before I left the house in the morning, just in case something went wrong. To get round this, I began to postpone until late morning or early afternoon business I had to attend to, along with meetings, appointments, and social events, etc. I soon found this to be very restrictive but the more I worried about the situation, the worse it seemed to get until I found myself almost housebound.

As time went by however, I got used to the changes in my body. I learned to recognise and understand all the new and different sensations I was experiencing. Eventually I started to cope a lot better with the way my post-op body functioned. Looking back, this was the stepping-stone I needed to put me on track to living a normal life again.

The second biggest issue I had in the early days was gaining confidence in my pouch. I was particularly worried about how it was attached to my body and how secure it was. My anxieties weren't helped early on by a number of embarrassing accidents. Just when I thought I had got things under control, I'd suffer a leak, or the pouch would become detached. I found these situations really debilitating; they knocked my confidence for six. Many a time I felt like I was right back to square one!

I eventually rebelled against my condition and how my stoma was dictating my life. Once I made this resolution, I quickly realised it was very much a case of mind over matter. I decided that I had to attend meetings, appointments and social events at specific times and just deal with the consequences if there were any. From that point on, my stoma took a back seat and my life gradually returned to normal.



During the course of my learning process, I discovered that while diet is very important when trying to control your bowel movements, knowing what you can and can't eat is not a thing you can be taught. It is something you must learn by yourself, as everybody's digestive system is different. For example, I have no problem with spicy foods, curries, etc. but if I have a meeting or appointment the next morning, I certainly WON'T have a bowl of vegetable soup followed by fruit the night before! Getting to know how your body copes with, and reacts to, various foods will reinstate an element of control over your bowel movements. I found this reduced my stress levels and sped up my recovery.

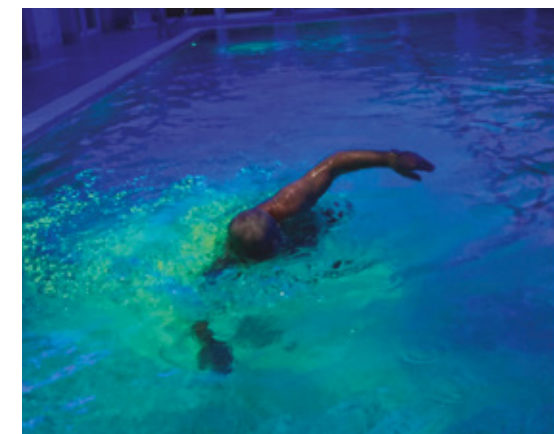
Another very important factor in living with a stoma is your mental attitude towards it. Your stoma is nothing to be ashamed of. I believe it's very important to develop this mindset, despite how hard this might seem. I once heard someone say: "Better to be alive with a bag than dead without one". That simple mantra helped me accept my condition. It is self-destructive to go through life feeling sorry for yourself and thinking "why me?". Instead, try to be positive and if you need to remind yourself to be so, then think how your life (and health) might have been, if you hadn't had the surgery.

As far as pouch confidence goes, in the beginning, I was also scared to go into the water when I was at the beach in case the water affected the glue securing the pouch to my body. Now, a few years later and after gradually pushing the limits, I find that during my daily exercise routine I can swim for 45 minutes in chlorinated water at 30C, followed by 15 minutes in a hot tub at 38C, five minutes in a steam room at 42C, and five minutes in a sauna at 50C. All this is interspersed with hot and cold showers and profuse sweating, yet the pouch remains totally secure (although like Tuppy (see pp. 35-37)

I also replace mine immediately after I've dried off). I think this demonstrates just how secure and water-tight pouches are. The only warning I would give relates to sun-bathing in very hot weather. I have found that sweat adversely affects the seal between your body and the pouch. So be careful, as we all know how it's nice to laze in the sun after a dip in the ocean!

Finally, on the odd occasion you have wind in company, don't get embarrassed about it, just look at the nearest person facing away from you, roll your eyes and shake your head gently. Always works for me!

Hopefully my experience of living with a stoma will help you deal with yours.





Annual Prize Draw



Dear Reader

In past years, your spring edition of Tidings included a book of raffle tickets for our annual prize draw.

The amount raised each year from the prize draw makes a significant difference to Colostomy UK and helps to run our support services including our stoma helpline and produce this magazine.

We are running the draw as usual this year but in a slightly different way. Rather than having a book of

tickets, we are using the entry form you can see on the opposite page.

To enter the prize draw you just need to complete the form, selecting the number of entries you would like to buy (each one costs £1), and then return it to us with your payment.

Your unique draw numbers will be allocated to you on receipt of your entry. Let us know if you would like to receive an email confirming these.

So why are we changing things?

Quite simply, it's to reduce costs so that more goes towards supporting the ostomate community. With the old way of doing things we had to pay to produce the raffle tickets. There was also an insertion fee for the magazine. Changing to the new way of doing things removes both these costs!

If you have any queries, please email fundraising@colostomyuk.org



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More opportunities to take part in surveys and have your say on the future of stoma care in the UK.

More access to our support literature and factsheets about all aspects of living with a stoma.

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*Please note, you can only have a maximum of 30 entries per raffle.

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Airport Travel Update

As you probably know, Colostomy UK has been actively working with airports across the UK to improve the travel experience for people who have stomas. Over the years, this has seen us regularly providing 'StomaAware' training to customer-facing airport staff and having input to airports' standard operating procedures. Libby, our General Manager, is also on the Civil Aviation's Access to Air Travel Panel.

With foreign holidays set to return this summer, we were very pleased to get the latest news from Heathrow's Sara Marchant (Service Manager – Passengers Requiring Support Service). The UK Government has also recently updated its travel advice: www.gov.uk/guidance/coronavirus-covid-19-safer-air-travel-guidance-for-passengers. Although Sara refers specifically to Heathrow, the excellent advice she gives can be applied more generally. This is what she said:

It is great to finally begin to see light at the end of the tunnel. Infection rates are dropping, and airline passenger numbers are starting to pick up again as people look forward to long-awaited holidays and family reunions.

At Heathrow, we have been working hard to make sure that everything is ready for more and more people returning to the skies. We have an array of COVID-secure enhanced cleaning regimes in place to keep everybody safe. One of the additional measures we have is an anti-viral coating on high-touch places (such as lift buttons) which are active for several months before they need renewing. We have hundreds of hand sanitisation stations all around the terminal buildings and we encourage everybody to continue wearing face coverings to protect themselves and others.

If you are planning a trip by air, there are a few things that you can do to help your journey go smoothly. Take a look at Heathrow's website before you travel. There is a wealth of advice, information and useful things to know before you travel. Information specific to accessibility and disability can be found at Accessibility and mobility help | Heathrow. Security can often be an area that people have concerns about. It is entirely optional, but you might wish to consider wearing a sunflower lanyard to indicate that you have

a non-visible condition. It will not give you any special privileges, it is simply an awareness-raiser but if you ask for help at any point during your journey, colleagues will do their very best to help you. They will also understand that you may need a little more help or time. If you are picked for a search by security, you may ask to go to a private room at any point throughout the process if you would prefer and can take somebody with you.

If you would like to make use of the Assistance Service at the airport please book it through your airline or travel agent a minimum of 48 hours in advance. Lastly, double-check which terminal you are flying from, and allow plenty of time so that you aren't rushed. Once you are through security, enjoy the many and varied retail and food and beverage offerings, and relax, you are on your way!

Hopefully, the above will be useful for anyone planning a trip this year. Please also remember to visit the Colostomy UK Website for updates. In addition, you can download a copy of our Travel Advice booklet. **To request a hardcopy, call our Admin Line (0118 939 1537) and we'll pop one in the post.**

Travelling with a Stoma

BY MERV QUICK

After being diagnosed with bladder cancer I had a urostomy in the summer of 2017. Recovery was reasonably quick. I was back driving after six weeks and starting to do normal things. Top tip:- if you are a tennis fan then plan your operation for June. First the French Open, followed by Eastbourne, then Wimbledon, and, lo and behold, you have got through the initial recovery period!

I digress. Apparently, a lot of people are concerned about travelling with a stoma. I thought about this and decided that nothing should stop my wife and I enjoying those bucket list trips.

A year later, having given time for things to settle, we went to Greece – a safe trip since we were visiting my sister-in-law. We had an enjoyable couple of weeks in the sun, and the Aegean Sea, during which I proved you could spend over an hour in the sea without one's pouch coming adrift! And you can buy special swim gear that has pockets to tuck your pouch away.

But what about those bucket list trips? Six months later saw us boarding a plane to Delhi for a 17-day tour taking in Shimla and the Golden Triangle. Naturally, going to India was a different kettle of fish to a trip to a safe European country, so a little thought and preparation was given to the medical side of the packing. Split your stoma supplies up, spread

them across different suitcases, and double the amount that you expect to use. I also have a small travel pack containing the essentials for a pouch change, which went into the hand baggage. The normal 50ml aerosol adhesive remover is allowed on board. I also took some adhesive remover wipes. Knowing there would be times I could be with a non-English speaker, I carried a travel stoma leaflet explaining in multiple languages, and some pictures, what a stoma is. Lastly, knowing I would be on the plane for 12 hours, I made sure I had a fresh pouch the day of travel and, as urostomy pouches come in different sizes, used a larger than normal one.

What of the trip? Fabulous and highly recommended. Travelling with a reputable travel firm, we had guides with us all the time, were looked after like school children, and had 5-star hotels and treatment all the way. Food, whatever your taste, was catered for.

It was not all blistering hot curries, even fish and chips was available in one hotel!

The itinerary commenced with a visit to Shimla, the summer home of the government during the British rule. The experience of the Shimla Toy Train (as it is called), a narrow-gauge railway which takes one from the plains to the mountains, is unlikely to occur anywhere else! After a couple of days in Shimla enjoying the views of the Himalayas, we travelled back to New Delhi to take in the sites of the Golden Triangle. Visits to forts, temples and mosques made a lasting impression.

All too soon, it was back to a rainy Britain, and having survived once, time to plan the next bucket list trip: Vietnam and Cambodia. Unfortunately, Covid-19 led to a cancellation! Will we ever get there? who knows.



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Donations allow us to continue focusing on the things that matter to you - supporting and empowering ostomates.

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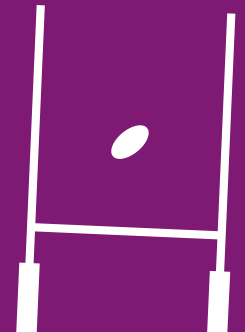


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Giovanni Cinque
Fundraising & Campaigns Manager
Giovanni.Cinque@ColostomyUK.org



Team Colostomy UK Are Back!

When the final whistle went in our game against Aldershot and Fleet in November 2019, we congratulated ourselves on an encouraging second year for the team. Since our formation in 2018, momentum had gathered on and off the field and we were beginning to feel that our wider message about stomas was being heard. Little did we know that the pandemic was lurking around the corner, ready to bring about an abrupt halt to all we had achieved.

The idea behind the team came from wanting to change perceptions about life with a stoma. It wasn't about getting all ostomates to play Rugby League – that would be ridiculous. Instead, through playing a tough collision sport, we wanted to demonstrate that anything is possible. Our aim was to inspire people who were post-op to take on and win their own battles. In the process we hoped that publicity about the team would provide a way to raise awareness about stomas more generally.

What started as an idea became a reality in July 2018 with a journey to Gillingham to play a Medway Dragons team. With six months having gone in to planning our first-ever fixture, there was a sense of achievement even before we stepped on the pitch. Our squad was a mixed bunch, from experienced Rugby League and Union players to complete novices. Some had stomas, some didn't. With all the laughter and camaraderie that followed, we realised we were on to something.



We knew if we could harness the enthusiasm from that day, there was the potential to make a difference to people's lives.

We followed the Medway game with a visit to South London Silverbacks before travelling to Featherstone Rovers in November for a game against a Physical Disability Rugby League (PDRL) all-stars team. If I could pick out a few events that helped change everything for us this was one of them. We had already started to generate a bit of publicity in the Rugby League and stoma communities. Playing at Rovers' home ground added further credibility to what we were doing. The PDRL game opened our eyes to what we could achieve. We were grateful too for the support of professional players Scott Murrell and Ben Kaye (brother of Team Colostomy UK player, Tom), who boosted interest through their engagement with us on social media.

It was through them that Paul Anderson, ex-England, Great Britain, Bradford, and St Helens star came across us. A private message from him via Twitter marked the start of an exciting few months. Early in his professional career Paul had a temporary stoma. We worked with Paul putting together his story in the hope that sharing it would spread knowledge about stomas to the wider public and, of course, give some profile to Colostomy UK and our Rugby League team.

Gavin Willacy, who is a freelance Rugby League writer took it from there and thanks to him Paul's story featured in Forty20, a mainstream monthly Rugby League magazine and shortly afterwards The Guardian. Just before Easter, Paul let us know that the BBC had picked up the story and Dave Woods the Corporation's Rugby League correspondent put together a great article which featured on the BBC News and Sports online platforms.

This was followed by an interview on the BBC 5Live podcast.

All this publicity put us in a good place at the start of the 2019 season, which began with another trip to Medway Dragons. This was followed by a game against Chorley Panthers in front of a really engaged crowd. Attendance was boosted thanks to professionals Josh Charnley and Owen Farnworth, who were our guest coaches for the day, and Anthony Gelling, who produced a fabulous video promoting the game and explaining what a stoma was. This reached over 100,000 people on Twitter alone. Our penultimate game of 2019 was against The Political Animals. This led to Colostomy UK's attendance at the All-Party Parliamentary Group Rugby League annual dinner, and a chance to spread the word to a different audience. We closed the season with our game against Aldershot and Fleet. Then the pandemic hit and put the kibosh on our plans for 2020.

We kept ourselves 'out there' by launching our new kit and promoting some of our players' stoma stories on social media. These were well received, which was no surprise, given the health challenges many have had to overcome before pulling on a Team Colostomy UK shirt. But without having a stage to showcase what we are all about made it difficult to keep things going. What we needed was for the team to play Rugby League again.

In the spring of 2021 as restrictions eased and community sport returned, we planned our comeback. This was exciting, but there was the nagging doubt at the back of everyone's mind at Colostomy UK that maybe the head of steam we built in 2018/19 had been lost

for good. There was also the question of how our players would respond. Would they still want to play after such a long break?

We soon found out... In August the team took to the field in a double header against an Invicta Panthers select team and another charity side, Robbie's Roos. The feeling of relief that day was massive. While there wasn't quite the fanfare that had accompanied our closing games of 2019, it was rewarding to see the team back in action. An off-the-cuff comment after the game against Robbie's Roos also thrust us back into the media spotlight, re-igniting that flame we thought we had lost. It was the simple request to take a photo of five of the team in their kit, but showing their stoma bags that did it. It turned out to be perhaps the most important photograph Colostomy UK has ever taken.

We shared the photo of players John Flood, Kav Ellison, Tom Kaye, Michael Adams, and Ed Rowland on social media the Monday after the game.

Very soon it had reached over 60,000 people on Twitter alone, attracting attention from not only the stoma and Rugby League communities but healthcare professionals too.

The comments we received allayed our fears. It was clear that Team Colostomy UK was well and truly back in town, empowering ostomates and spreading awareness:

'Love heroes like these, rising above, raising awareness, and beating back myths and discrimination.'

'Love this body positivity! I hope it helps others towards the same.'

'What a fantastic way to raise awareness and show that you can still live your life your way.'





The noise the photo made had only just started to die down when we travelled back to Chorley in mid-September for another game. I invited The Daily Mirror's Rugby League writer Gareth Walker to the fixture with the hope of encouraging him to talk about us. After the game he spoke to players Tom Kaye and Kav Ellison about their stoma journeys and the impact the team has had on them. He was impressed enough to promise an online feature the following week. It was also great to hear that he thought our standard of play was promising!

The next week was a blur of good news with confirmation on the Tuesday night that the story would also feature in The Daily Mirror's print edition as a full-page spread. On Wednesday we discovered that The Daily Express and The Daily Star had also published colour features with the photo we took at the August game as the centre piece. Wednesday afternoon saw another 5Live feature, an appearance on the Loose Forward podcast, and a feature on Czech Network News. Wow! Our best guess is that in the two days that followed we reached an audience totalling somewhere in the region of two and a half million people (a million of which was through print media): a truly phenomenal statistic.

We ended 2021 with another high. 15 years after his retirement Paul Anderson put on a Team Colostomy UK shirt and played for us in our final game of the season against Bramley

Buffaloes. Sharing the field with an ex-Rugby League star was a dream come true for our players. It also led to more column inches.

We have some exciting plans for 2022, so be sure to follow the team on social media. What drives us is the knowledge that every time we play, someone out there who has had stoma surgery and is feeling worried or anxious about the future will hear about us for the first time. They will read our players' stories and be empowered to face their own challenges head on. There will also be someone else we reach who beforehand won't have known what a stoma was or the challenges that ostomates face; changing perceptions is just as important.

After the Chorley game, Kav Ellison had this to say:

'It's hard to deny how successful Team Colostomy UK has become... The awareness, the publicity, the money raised, the enjoyment had - all huge.'

It's a brilliant movement to be a part of, but we can't forget the bigger picture: to help others, educate the ignorant and prove that anything is still possible.'

If we stay true to Kav's words I'm confident we'll continue to make a difference for people with stomas.

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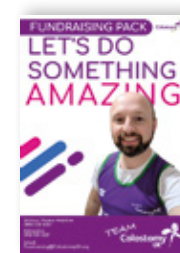
Caring for a person with a stoma



Caring for a person with a stoma and dementia



Colonoscopy through a stoma



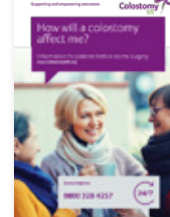
Fundraising Pack



Healthy Eating



Helpline Cards



How will a stoma affect me?



Irrigation Booklet



Irrigation DVD (nurses)



Irrigation DVD (patients)



Legacy Flyer



Living with a stoma



One to one



Ovarian Cancer and stomas



Pain and discomfort



Parastomal hernias



Rectal discharge



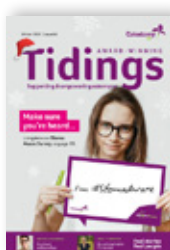
'Sam has a stoma' colouring book



Stoma friendly toilet guideline and stickers



Stoma reversal



Tidings magazine



Travel advice



Travel certificate



Tri-Charity leaflet



Welcome pack



INTRODUCING

Stoma Squad

Colostomy UK has been campaigning to raise awareness about stomas for many years now. It's very much a part of our DNA as a charity and will continue to be so for the foreseeable future. This is because until it is more generally understood what a stoma is and why people need stoma surgery, ostomates will continue to encounter barriers to living their daily lives.

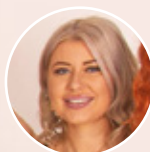


retroperitoneal liposarcoma which is a rare form of cancer. I had a large tumour measuring 50cm by 25cm which weighed almost two stone. The only treatment was surgery. My surgery was undertaken on the 22nd July 2021 during which the whole tumour was removed along with my right kidney, my right ovary, and, in order to give clear margins to prevent the cancer spreading, part of my liver, bowel, intestine and muscle. When I was taken into recovery from surgery it was noticed that I was haemorrhaging so I was rushed back for transfusions and to stop the bleed. The origin of the bleed was the bowel which had been caught and to stop the bleed a stoma was developed.

It was a shock to be told I had a stoma but am grateful that it saved my life. I wanted to be part of the photo shoot and fundraising campaign to bring about awareness and show that a stoma may be needed for a wide variety of reasons and at any age.

There are all sorts of ways to bring the message about stomas to the wider world, but one of the best is through the sharing of powerful personal stories. This requires courageous people. If you have been on social media recently, or perhaps watch BBC Midlands, then you may have come across Stoma Squad. The squad is comprised of a group of ladies, at different stages of life after stoma surgery. Together, they have done their bit to raise awareness through a photoshoot in which they proudly displayed their bags. Just like Team Colostomy UK's Rugby League team (see pages 24-26), the coverage they have received has been impressive and reached many people. And, if that wasn't enough, they have been fundraising for Colostomy UK at the same time! If you want to support them and us, then visit <https://gofund.me/be441f30>.

With Stoma Squad featuring on this edition's front cover, we thought you would like to know a little bit about them:

**Hey, I'm Jody**

I'm 28. I suffered from very severe bladder and bowel incontinence due to having an auto-immune disease. In March 2020 I had a surgery called CLAM which helped resolve my bladder incontinence meaning I had to self-catheterize every four hours. Much as this made my life feel a lot freer and more enjoyable, I was still left with bowel incontinence which made day-to-day life very difficult.

Between myself and my surgeon we decided to go ahead with stoma surgery, which I had in October 2021. After having my surgery and as I was adapting to a new way of life, I joined an online stoma support group where I quickly learned how many people, both men and women, were suffering mentally with having a stoma and adapting to it. I also found that people couldn't understand why I had or needed a stoma being so young and looking so 'well'. I've regularly had

to explain the numerous reasons people of all ages might need a stoma. There isn't much information out there regarding stomas. This led me to the idea of a group photoshoot of people with stomas in the hope that others with stomas would see it and feel less alone and more comfortable in themselves. The hope too is that people in general will see it as well and as a consequence won't be as quick to judge others and not second guess why an apparently well person is using an accessible toilet.

I put forward the idea on a support group and got a lot of interest. This ultimately led to me arranging a date with a lovely photographer and the start of a fundraiser where all donations go to Colostomy UK. I have made friends for life with the incredible women joining me in this shoot! Let's break the stigma regarding stomas and start sharing more positivity.

**Hi, my name is Kayleigh**

I'm 27, and I spent ten years misdiagnosed, with

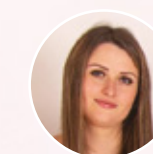
GPs having me believe my illness was in my head. I was eventually diagnosed with Crohn's Disease, lost most of my intestines and gained a stoma! How you choose to react to your stoma is entirely up to you, but personally, it's given me a life worth living and connected me with so many wonderful people. I want others to see the beauty in them that I do. After all, stomas save lives. Just remember, you're not alone in this, we're stronger together!

**Hi, I'm Anna**

I'm 22. I was diagnosed with Ulcerative Colitis in 2018 whilst studying

at university and was given my stoma in 2020 after having emergency surgery. My stoma saved my life,

and I am forever grateful for it! I decided to do the photo shoot to meet other ostomates like myself and to raise awareness of stomas to show that not all illnesses are visible and younger people have stomas too.

**Hi, I'm Emily**

I'm 28. I got Ulcerative Colitis while pregnant. I spent a month in hospital and two

years trying all the meds and barely eating or leaving the house. I had my ileostomy in lockdown after the pain got unbearable for me. I'm doing this photoshoot for my own self confidence as well as to spread awareness.

**Hello, I'm Catherine**

I'm 64 years old. My story is a little different in that there was not actually

anything wrong with my bowel. In June 2021 I was diagnosed with

**Hi, I'm Jan**

I'm 65. I was taken to hospital for emergency surgery after having a twinge in my side,

which turned out to be a caecal tumour. This was removed, and an anastomosis performed. The surgery wasn't successful, and I got sepsis. I was then taken back to theatre a week later where I woke up having had an ileostomy which, to say the least, was a huge shock. I was in ICU for a week with continued sepsis. It was a rough six weeks, but my stoma saved my life for which I am very grateful. The stoma groups have got me through some tough times and doing this photoshoot will hopefully help others to see you can live a happy life once you get the hang of it. I'm eternally grateful to still be here and connected with others who totally understand. It will hopefully give others a different perspective, that there is life after stoma surgery!



sticks like...



Hello, I'm Gaynor

I'm 56 years young. I had a slow bowel and had to have twelve laxatives a day. Then in 2015 I had a sub-total colectomy. In January 2018 I was going to the toilet between 10-20 times a day and could hardly leave the house. From February I had to work from home, then in September 2018 I had surgery for a stoma to improve my quality of life. I spent a month in hospital and had to be tube fed. It took me a day to eat a jelly cola bottle! After 'Shamira' my stoma was formed, I found I could eat anything and do anything again! I am so grateful to have my life back and I feel so lucky. When Jody told me I was going to be in the photoshoot I was truly honoured. I feel like I now have nine new friends each of whom is so brave and inspirational and that we can achieve anything.



Hi I'm Jeanette

I'm 57. In 2020 I attended a routine bowel screening, where I was found to have multiple bowel polyps. With this and my family history, I was referred to the Familial Cancer Service, where following genetic testing I was diagnosed with Attenuated Familial Adenomatous Polyposis (AFAP) – an inherited condition where bowel polyps have the potential to develop into cancer, caused by an abnormality in the APC gene. To prevent this, I underwent a pan proctocolectomy and ileostomy in February 2021 where 'Betsy' my stoma was born. Until this happened, I had no idea of the variety of reasons why people have stomas. The screening has enabled me to be in control, albeit life changing when I had no obvious symptoms.



Hi, my name is Elizabeth

I was diagnosed with Ulcerative Colitis in 2019. After multiple hospital admissions and failed treatments, I had emergency surgery to remove my colon in 2020. I couldn't wait as I wasn't living my life. My stoma has given me the opportunity to live a better quality of life. I wanted to do the photoshoot to raise awareness for fellow ostomates.



Hello, I'm Casey

I'm 30. I was misdiagnosed all my teen years with IBS and finally had a correct diagnosis at 21 when I was pregnant. I had my first flare up during pregnancy and was treated with emergency care for me and my unborn baby. I was in remission for seven years and had my second flare in 2021. Medication did not help and I had a lot of small bowel removed. It was either a stoma or my life. We are strong, and I'm glad I had the chance to meet other brave women and for us to spread awareness.



We think the Stoma Squad are amazing and we're really grateful for both the support they are giving us and for how they'll inspire others facing their own journeys after stoma surgery!



seals like...



volunteers



Maxyne McGinley
Volunteers & Community Manager
Volunteer @ColostomyUK.org

Meet Max!

Maxyne became our new Volunteers and Community Manager late last year after having first worked as a contractor. Now that she's got her feet under the desk, I thought it was about time we introduced her to the readers of Tidings. I 'interviewed' Max the week before our office move, surrounded by packing boxes and dust. We were at the stage where chairs and desks were at a premium so, ever the gentlemen, I let Max sit on the table, while I took a seat on the floor!

Richard (Editor):
Tell me about yourself

Maxyne: Having been in and out of hospital most of my adult life and undergone two lifesaving operations, I decided to take a trip to India to see whether I could help myself rather than continue to be at the mercy of the poor old NHS! I travelled to Kerala and stayed at an Ayurvedic hospital where they proceeded to rebuild me from the inside out. I witnessed several little miracles in terms of how they were helping people to heal. After too short a stay I returned home. Three months later my appointment at Frimley Park Hospital revealed my condition had improved by almost 50% - in only three short months. For me this was nothing short of another miracle. So, I decided to leave the corporate world which had been

my home for most of my working life and pursue a new vocation in Ayurvedic therapies. Four years on I am physically the healthiest I have been since my late teens and my love for Ayurveda continues.

R: What do you like to do in your spare time?

M: I have mastered the art of 'pottering' and can spend hours moving furniture around just to accommodate a new table lamp! I get lost in decorating and gardening and enjoy experimenting with recipes, some work out better than others ...! I study Ayurveda and occasionally adopt the odd Yoga pose and I love walking.

R: What were your first impressions of Colostomy UK (CUK)?

M: I found the Office Team and Volunteers a warm, friendly, dedicated bunch with CUK running through their veins.

R: Now you've had a few months to settle in, have these impressions changed?

If anything, they have been cemented further. I recognise that CUK couldn't have achieved what it has without the amazing people who give up their time and energy to volunteer.

R: What are you looking forward to as Volunteers' Manager?

M: Retirement!

There is a great pool of knowledge and expertise amongst our volunteers that could be drawn upon to help drive CUK forward. From the start my plan was to speak with them all and get to know them on a one-to-one basis, their experience, their interests, their thoughts on CUK and how we can support each other better. This is something I plan to continue in the coming months.

R: Tell me about the plans you have for our volunteers

To increase the number of volunteers in all areas of volunteering; to broaden the demographic; to expand the skill set through individual training and development; to build on and promote an inclusive 'One Team' approach.

R: What do you think will be your biggest challenge?

M: Only working three days a week I'm trying to find a balance between blue sky thinking and the daily needs of the role.

R: Finally, what would you say to someone who is considering becoming a volunteer?

M: Don't hesitate to get in touch!



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Tuppy Takes the Plunge!

BY RICHARD BIDDLE



'I'm allergic to chlorine', 'I've got a paddle injury' and 'It's the wrong time of the month', are just some of the excuses I tried as a child to get out of swimming. The latter was perhaps pushing the bounds of credibility too far. Needless to say, it didn't wash with Mr Lewis the P.E. teacher.

It wasn't that I didn't like swimming. Instead, it was the thought of getting into the school pool. The water was just a little too cloudy for comfort and there always seemed to be 'bits' floating around that you could accidentally swallow.

The barriers ostomates face around swimming are far less trivial. Two stand out. First: fear of the public gaze. Let's face it, most people don't relish donning in public just a swimsuit or speedos, but when you add a stoma bag to the mix it's a whole new level of vulnerability. Even if you manage to get into the pool unnoticed, there is still the trip back to the changing rooms to navigate. Second: the worry of a bag malfunction. What would happen if it leaked or came off? It doesn't bear thinking about. How could you ever live down the embarrassment of causing a pool evacuation? You would never return to the same pool again, that's for sure.

At Colostomy UK we don't underestimate the impact this can have on people.

Such concerns can put an end to swimming as a pastime. The knock-on effect is less or no physical activity, which as we know is important for a range of reasons, including keeping weight in check and preventing parastomal hernias. There is also the





mental side of things to consider. When you are coming to terms with the aftermath of life-changing surgery, it's never helpful to feel denied the things you previously enjoyed. When we ran some ostomate-only swimming sessions before the pandemic, one man owned up to fact that it was the first time he had been in the pool since his surgery, which was nearly twenty years ago. Wider family and friends can suffer too. It also transpired that it was the first time he'd ever been able to enjoy the water with his young son. Thankfully the whole family are now frequent swimmers (Tidings summer 2018).

Joining one of our ostomate-only sessions is a safe way to dip your toe in the water after surgery. It can prove enough of a confidence boost for some to get them swimming regularly again. But what happens if you don't live near the pool we hire out, or can't make the session? How do you overcome the hurdles without this sort of help? I caught up recently with Tuppy Hill who has done just that and gone it alone. Tuppy had stoma surgery in December 2018 following bowel cancer and had her first post-op dip in February 2019. She has never looked back. Indeed, last year she took part in a 10K Swimathon,

raising money for Cancer Research UK and Marie Curie Cancer Care. Hopefully Tuppy's story will encourage all our would-be swimmers to get a taste of chlorine again.

Tuppy, who lives in Dorset, was diagnosed with bowel cancer in August 2017, after noticing changes in her bowel habits. She booked to see her GP and things moved quickly from there. She had a colonoscopy two weeks later and began chemotherapy in late September. This finished in December and was followed with radiotherapy. The aim was to shrink the tumour in preparation for its surgical removal. When Tuppy went to see her consultant in April 2018, he could find no evidence of the tumour. A second opinion confirmed this and so Tuppy entered a period of watch and wait, which entailed regular screening. Unfortunately in October 2018 this picked up that the cancer had returned.

Tuppy has been a keen swimmer all her life. Prior to her diagnosis, she was (and still is) a member of a local sports centre. On learning she had cancer Tuppy was very concerned that her treatment might prevent her swimming. This played on her mind to such an extent that in the end she

decided to contact the sports centre. She spoke initially to the manager, who she says was very supportive. So much so in fact, that the centre suspended Tuppy's membership without any retainer during the 'watch and wait' period, but still allowed her to swim. Plucking up the courage to have this conversation also paid dividends further down the line when Tuppy learned she would need stoma surgery. In effect it opened lines of communication, which made talking about stomas and swimming all the more easy for both parties. From speaking to Tuppy I know that having the support of the centre's staff meant a great deal to her. It also boosted her confidence when it came to returning to the pool after her op. The advice to be upfront and open in this way is something I have heard many times over the years. But just how do you go about being 'open'? For some people talking about the fact they have a stoma is in itself almost too daunting to contemplate.

I put this Tuppy, so readers could hear her thoughts on the matter. She acknowledged she didn't find it easy but in the end her desire to keep swimming proved motivation enough. She said the thought of having that first conversation with the sports centre was excruciating, particularly as she went into it harbouring concerns about bag leaks and possibly being told her swimming career was over. Tuppy used the analogy of Wurzel Gumidge to explain her approach. Readers old enough to remember Wurzel may recall that he would put on different heads, each of which gave him a specific power. Well Tuppy put on her 'business head'. This helped her to detach from the emotion and deal with things as she might have done a business problem. In chatting further around the issue of being open, we both thought that another approach that she could have used would have been to email the sports centre or written them a letter, explaining the situation and asking for a call back.

We then talked through Tuppy's return to the pool. It was an event she planned carefully. As well as talking



to the sports centre she also spoke beforehand with the stoma care nurses at Poole Hospital who were equally supportive and encouraging. They also advised on more practical issues such as ensuring she had suitable (supportive) swimwear. Tuppy changed into her costume before going to the sports centre. When she arrived the receptionist greeted her with a box of chocolates and card which said inside: 'You are an inspiration'. This effectively sealed the deal, there was no backing out now! Tuppy says she undressed quickly and, being very conscious of the bulge in her costume, slipped as quickly as she could into the water. The stoma care nurses had advised her to take it easy to begin with and this was advice that she followed carefully as she was (and still is) worried about parastomal hernias. After doing a number of lengths, she got out and headed straight for the changing rooms where she got dressed and left immediately.

She describes the experience as 'weird', but found that having crossed the initial hurdle her confidence grew from that point onwards.

Since then, regular swimming (pool and sea) has led to some adjustments in Tuppy's routine. She has learned that although stoma bags are waterproof, if you keep the same bag on after a swim it gets your clothes wet. She now does a bag change at the pool. At first, Tuppy also didn't eat anything prior to going swimming. But now she has a better understanding of her stoma she doesn't adhere to this rule anymore. Since August 2019, Tuppy has also been irrigating, which she says has further boosted her confidence. It allows her, for example, to use a midi / mini / plug / cap or bag. Having swum so much now after surgery, Tuppy has also come to the conclusion that people 'don't look' and so don't notice you have a bag. For her the whole public gaze thing was really difficult to overcome. Finally, she felt that while returning to swimming was something she preferred to do alone, others might want to consider taking a relative or close friend with them for moral support. In essence, you should do what feels right for you.

As our conversation drew to a close I asked Tuppy to explain what returning to swimming has meant for her. As a charity, Colostomy UK is keen to push being active, but there is nothing like personal testimony. Tuppy says that the benefits have been enormous, both from a physical and mental point of view. For her, the latter has been the most important. By her own admission, she is by nature an anxious person, but when swimming she finds she can't let her thinking go into overdrive. Instead she focuses solely on the swimming and counting lengths.

No-one would be stupid enough to suggest that going swimming after you've had stoma surgery is easy. There are both practical and mental hurdles to cross. But as Tuppy's story illustrates, it is possible. If you are one of those who have been hovering by the side of the pool, then hopefully reading about Tuppy's experience and the advice she gives, will be enough to push you over edge...





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Dealing With Life's Curveballs

BY RICHARD BIDDLE

Last summer Dianne and her husband decided to take a holiday. The plan was to use their campervan to travel part of the NC500. This is the 516-mile scenic route which runs round the north coast of Scotland. It started well but then, as they were parked up on the east coast enjoying the morning sunshine and lovely scenery, life threw Dianne a curveball. Less than 24 hours later she had a stoma. Coping with emergency surgery of any kind is never easy. Not only is there the initial shock to come to terms with, but also the aftermath and the impact on life. There is no preparation time. With emergency stoma surgery it is perhaps doubly difficult because very often the patient doesn't know what a stoma is. They just wake up with one. This was certainly how it was for Dianne. It was on day four in the intensive care unit that she felt her pouch.



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TIDINGS 65 | SPRING 2022



What follows is a tale with many twists and turns, and more than a few curveballs. It isn't just about how Dianne came to have a Hartmann's in July 2021. It is also about how she has coped afterwards living, as she does, in the very same campervan she and her husband took with them to Scotland. Dianne's past, and how she came to live in a campervan, is also an important component of the story. Although I'm no psychologist, when Dianne told me of the life she had led and the difficult times she and her husband had faced, I couldn't help thinking that it somehow equipped them to deal with what happened and gave them the mindset to tackle life afterwards.

Let's start with the past. Dianne, who is now in her mid-seventies has been married for 52 years. She was born and started married life in the West Midlands. Her husband, who is a musician, was heavily involved in the Blues and Big Band scene so prominent in this part of the country during the '60s and '70s. As this scene started to wane, they headed south and bought a house in Cornwall, where they stayed until the mid-eighties, by which time they had three sons. It was at this point that campervans first made their appearance in Dianne's life. In what some would describe as a bold move, others a foolhardy one, Dianne and her husband sold up and bought a VW Camper Van, with the intention of taking a six-month road trip around Europe. This ended up lasting two years, during which they spent a lot of time in Turkey and also Northern Cyprus, where they settled for a spell. While away, their eldest son (who was still in the UK) married a Cornish girl. Shortly afterwards they became grandparents.

A year later in 1990, Dianne and family returned to England, where they bought a house in Bideford. Dianne says they very quickly settled back into 'normal' life. Their two younger sons finished school, before flying the nest. Dianne and her husband went to work. By 1997 and with all their sons now grown-up, itchy feet again set in. They



both missed Cyprus and so, with the confidence that comes with having done something before, they sold up again and moved to Northern Cyprus. Their younger sons joined them there and worked for a while, before both returned to work in the UK. In 2001, their youngest son came back to visit them on route to south-east Asia. It was shortly after this that the first of two family tragedies struck. Thomas died unexpectedly in Thailand; he was 22 years old.

Their middle son Benjamin was staying with them when they received the news. As you would expect, it devastated the family. As they attempted to recover, they decided to leave Cyprus. Rather than return to the UK, the couple bought a wood and stone house in the mountains of Bulgaria to renovate. However, any hopes they had that such an idyllic location might help them to salvage their lives were sadly shattered a few years later, with the sudden death of Benjamin, their middle son.

Dianne says that at this point she and her husband had had enough. With Benjamin having spent time with them in Bulgaria, they couldn't face the prospect of staying there any longer, and so once again decided to move on. This time their travels took

them to Asia where they spent five or so years. It saw them settled for a while in a retirement complex in Malaysia, as well as travelling extensively. This included trips to Thailand where their grandson, now grown up, was teaching. Then, in a now familiar pattern, Dianne and her husband sold up again. They purchased another campervan and travelled to the UK via Morocco and Spain, arriving back in 2019.

Home has been their campervan ever since, which they keep on a fixed plot at a campsite. This means they have access to toilet facilities, somewhere to do laundry and can heat the van, which Dianne says is important now they are a bit older. Although living in a campervan is not to everyone's taste, it does have certain advantages... one of which is that you can take your home on holiday. Just think, no packing! This brings us to last year's fateful tour of Scotland.

If you remember, Dianne was enjoying the sunshine and scenery of the east coast at the time. She was fine in the morning when she and her husband took a stroll along the shoreline. However, that evening, without warning, she started to suffer from horrendous abdominal pains and vomiting. Sensing things were serious, Dianne's husband tried calling for an ambulance, but after the fourth attempt he gave up. Local enquiries established that the nearest hospital

with an accident and emergency department was 50 miles away in Inverness. With travelling coming as second nature to both of them, Dianne's husband didn't hesitate to put the campervan into gear and rush Dianne to the hospital. In Dianne's words he 'drove like crazy' while she lay on the bed in the back, writhing in agony. She was immediately admitted and had what turned out to be life-saving surgery the next morning, after it was discovered she had a stercoral perforation and sepsis. This type of bowel perforation is caused by faecal impaction. It is rare and has a high mortality rate.

Dianne spent 17 days in hospital, during which time she also developed a large parastomal hernia. Once discharged she had to attend the hospital as an out-patient for a further month. This was to allow her wound to be drained and redressed, and additionally, for the first two weeks, so she could have injections in her stomach. For many patients and their families, a lengthy hospital stay followed by an extended period of daily visits would present logistical problems. This wasn't so in Dianne's case, as the hospital kindly allowed them to keep their campervan in the

car park for the full six weeks! During this period, Dianne says her husband was a rock. He cooked them simple meals and accompanied Dianne as she got her strength back through daily walks around the car park. Then, quite incredibly, after a final check-up with the stoma care team and her consultant at Raigmore Hospital, Dianne and her husband resumed their holiday. They managed to get round most of the north coast before returning to their campervan's fixed plot.

When I spoke with Dianne just before Christmas, she had been in touch with her GP and the local hospital's stoma care department. She was waiting on a consultant appointment to assess her hernia for repair and/or the possibility of a reversal. Now that she is over the initial shock of what happened and how low she felt in the aftermath, Dianne is up for life again. She is also upbeat about residing in a campervan. For her, the only stoma-related issue has been around the lack of a flushing toilet inside. Thus, when she does a bag change, she does this over a large yoghurt pot and hopes

her aim is true.
I'm sure many people regardless of whether



they are ostomates, would find the lack of space a problem, but not Dianne. Having lived such a daring, challenging and at times difficult life, such things simply don't faze her. Indeed, the only thing Dianne has really struggled with since her surgery is not being able to swim; her hernia is too big to allow this. While they lived in Malaysia, Dianne swam upwards of three miles a week and found this to be great mind therapy for dealing with the loss of her sons. Let's all hope that her appointment goes well, and that a trip to the pool isn't too far off for her!





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Giovanni Cinque
Fundraising & Campaigns Manager
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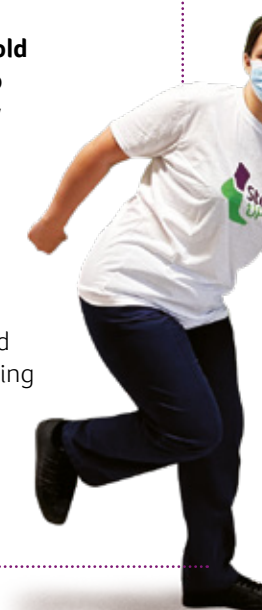
Supporting Colostomy UK

Every month, dozens of people make the choice to hold an event, take on a challenge, or ask for donations to support Colostomy UK. We are a self-funding charity so without their help we wouldn't be able to support people with stomas in nearly as many ways as we do.

Every £1 you give really does make a difference. This issue features just a few of the people who have supported us recently.

Please consider raising funds for Colostomy UK too, and don't worry... you don't need to even think about running a marathon or swimming 5K if you don't want to!

There are loads of ways you can support us. Visit www.colostomyuk.org/get-involved/fundraising/ for details on how you can make a difference.



Step Up for Stomas Update

We're thrilled to announce that the final amount raised from our 2021 'Step Up for Stomas' challenge was a **Fantastic £51,515!!**

A huge thank you to everyone who took part. Rest assured that the funds raised will help us better support people with stomas.

It's not long until 'Step Up for Stomas 2' launches. Keep an eye out for the next issue of Tidings for more details!

Clothing Collections

Thank you to everyone who donated their unwanted clothing and other items to Colostomy UK through our partnership with ICollect Clothes. In 2021 we managed to raise over **£13,000** and it would be great if we could do the same again this year!

Don't forget, if you're planning a clear-out, then as well as clothes you can also donate your unwanted paired shoes, linen, bedding, towels and curtains too. It all generates much needed funds for Colostomy UK! ICollect Clothes also collect accessories (bags, belts, hats, scarves), books, DVDs, CDs, soft toys, electronics, and small domestic appliances.



If you live in Greater London, the west Midlands or Merseyside you can book a collection online at icollectclothes.co.uk/donate/colostomy-uk or by calling **0344 879 4417**.

For all other areas give them a call and they will be able to advise when they will be collecting near you.

Virtual Reality Fundraising!

It's great to see some of the fantastic ways people are fundraising for us.

We love the Colostomy UK branded cars that were designed by the Asylum VR team for two 24-hour charity drives. The team raised over £700!



Thank You

We'd also like to thank the following for their recent support:

Francesca Aproskie who raised £120 from her charity Zumbathon; Karen McGuiness who raised £250 from her 5K sea swim; Kench Accountants whose dress-down days raised £112; Shropshire BOTS Stoma Support Group who donated £500 as a result of their annual open day; M & D Parsons who donated £300 raised at their charity garden party; Charlotte Crossland who raised £648 from competing in the Yorkshire Marathon; Deborah Taylor whose Lincoln 10K run raised £540; and Xena Marshall who completed the Loch Ness Marathon raising £476.



Rowing the Channel...

Good luck to Jo Prance who is taking on an 'oarsome' challenge on 12 March, by rowing 33km on an indoor rowing machine - the distance of the English Channel.



Jo is doing it to support her friend Fiona who will be rowing beside her. Together they are rowing in memory of Jane, Fiona's beloved sister, a keen rower and sportswoman.

Jo said: "Fiona and Jane had joked about rowing The Channel so I'm helping Fiona fulfil her legacy to Jane while fundraising for Colostomy UK, a charity that supports people living with a stoma like me".

You can donate to Jo's fundraising page here <https://gofund.me/446F2516>



Stamps to be cut/torn from recent mail.

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

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

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

Quaternx1 01-000-00 Stamps | Date of Publication: June 2021 | Copyright ©2021 Colostomy UK | Registered charity no. 1113471



Shaped for a life more ordinary

NaturFit®, the one-piece stoma pouch range from Opus Healthcare.

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Scan me or visit opus-healthcare.co.uk/evaluate



NaturFit®

opus-healthcare.co.uk



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

Ensure you always have access to a toilet by purchasing a Radar Key and Photo ID card. Through the with the National Key Scheme, Radar keys open the doors to over 9,000 accessible toilets in the UK in places like shopping centres, pubs, cafes and department stores. A Colostomy UK Photo ID card, which is endorsed by Disability Rights UK (and displays their logo), this can be helpful if you need to use accessible facilities urgently, particularly if they aren't part of the National Key Scheme.

To order a Photo ID card you will need to include a copy of your prescription or delivery note as proof of eligibility and a passport sized photo.

To obtain a **key or a photo identity card** please **complete the form and declaration below**, or visit: **www.colostomyuk.org/information/radarkey/**

Title: _____ Address: _____
Name: _____
Tel: _____
Email: _____ Postcode: _____

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

Signature (or carer signing on behalf of the person name above): _____ Date: _____

Please **tick** as appropriate:

- ☐ I would like to receive a Radar Key £4.50 ((inc. postage and packing).
☐ I would like to receive a photo ID card for £6.50 (inc. postage and packing) and enclose a passport photograph.

Return all required items to: **Colostomy UK, 100 Berkshire Place, Winnersh, RG41 5RD. Cheques should be made payable to Colostomy UK.** For payment by credit card, send your documents in the post with a contact telephone number, we will then call you to take a card payment when received. (If you have any queries or would like to pay by credit card, please contact **Colostomy UK** office: **0118 939 1537** or **info@ColostomyUK.org**).

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 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 chequemade payable to Colostomy UK, to:

Colostomy UK, 100 Berkshire Place, Winnersh, RG41 5RD
or you can purchase online at: www.ColostomyUK.bigcartel.com



Title: _____ ☐ I enclose a cheque or postal order made payable to Colostomy UK
Name: _____ ☐ Please debit my Visa/Mastercard/Meastro Card with the amount specified
Address: _____ Card number: _____ (Meastro only)

Postcode: _____ Expiry date: _____ Security code: _____ Start date: _____ Issue No. _____

Tel: _____ Signed: _____ Dated: _____
Email: _____

Please allow 30 days for delivery.
Colostomy UK, 100 Berkshire Place, Winnersh, RG41 5RD | Charity No. 1113471 | VAT No. 917079312

Your Letters and Emails

Editor's note:
Thank you to everyone who has been in touch. I have received many e-mails from people praising the last edition. This was of course lovely to receive and led to lots of smiling faces when I shared this feedback with the editorial team. Here is a selection from the mail bag.

Dear Editor,
I would like to thank all your volunteers for providing a 24-hour stoma helpline. It was most reassuring to know I could talk to experienced ostomates at any time. The nursing I received during nearly a month in Salisbury Hospital was outstanding, and the intelligent flexibility of the stoma department must be a model of good practice. Fortunately I had very little difficulty adapting to a stoma, and look forward to its eventual reversal.
The story in your recent issue of the first stoma operation in 1820 without anaesthetic does not bear thinking of. And the fact that the patient survived was all the more remarkable. Most interesting.
Yours, M M

Hi there,
I am writing following Sue Lennon's article 'Let's Talk About Sex' that appeared in the summer 2021 edition of Tidings.

I have had a stoma since I was 55 (15years). I had 12 lots of chemo and six lots of radiotherapy over about a year. I was told by my surgeon that this can have serious effects on the body producing testosterone. This proved to be so for me. I went to my lady GP who was great and referred me to an endocrinologist. After some simple blood tests, I was prescribed Tostran gel. This is rubbed into the side of my tummy. I was monitored for a short while so the correct amount could be administered. I've been fine since. There are many other treatments available too, which we discussed at my support group. My message to readers is don't be embarrassed to go and see your GP.

Kind Regards, John

Dear Editor
Having had a permanent colostomy for over six years now I am very much aware of the cost to the NHS of the equipment required by us ostomates to try and live a normal life.

I'm fortunate that from quite early on I was able to self-irrigate.
I just thought I would send a little money saving tip I do, in the hope it helps others too. I have attached some photos to aid my descriptions.

I use Accubond strips to help keep my stoma caps on when I exercise, run, swim, etc. At first, I found I was getting through quite a few. Now I find that by cutting them into pieces I am able to use a lot less and they work just as well as the full strips.

I imagine for people with full stoma bags this would not work so well, but for me with a small stoma cap on most of the time it works really well. Using far less strips and adhesive spray I hope will save money for the NHS in the long run.

Kind Regards, Anthony Robinson





Dear Editor,

I am writing this as a 20-year-old who had an ileostomy in 2020. I've had my stoma long enough now to know what I can and can't eat. I personally avoid food for example with skins on, unless peeled, dried fruits and nuts and seeds, as these can cause my stoma to block.

I don't know if any other readers of Tidings have noticed this, but I am finding more and more when I go out for a meal that there are often very limited menu choices for people with stomas. The options available always seem to include a vegetable I can't eat, or the food is covered with seeds, seasonings etc. I tried McDonald's the other day and there were only a couple of things on the menu I could eat

because of the seeded buns. When I have asked restaurant staff if things like seeds and cucumbers can be left out, they seem to struggle to understand why this needs to be done without me explicitly stating I have a stoma, which I'm reluctant to do. I feel that places selling food could try to accommodate our diets more, or at least have some sort of knowledge in this area, so that if I ask for no seeds or peels, it isn't considered an unusual request.

I was wondering if it's just me who feels like this or if it's a common problem? And if it's common what might be done about it!

Kind regards, D McGrath

We look forward to hearing from you, our readers:

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

Write a letter to:
The Editor,
Colostomy UK,
100 Berkshire Place,
Winnersh,
Wokingham,
Berkshire,
RG41 5RD.

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.

Picture perfect

Talented artist, ostomate, and supporter of Colostomy UK, Emily Hackworthy has created a beautiful and striking set of 'outline body' prints representing ostomates.

Her artwork of male and female forms with either a colostomy or ileostomy are now available for sale via our online shop, and Emily is kindly donating all the proceeds to Colostomy UK.

You can order online at:
<https://colostomyuk.bigcartel.com>

Please allow 28 days for delivery. Purchase is for print only. Frame not included. Print size A4.



Every 39 minutes someone in the UK has stoma surgery.



**Can you help us to give them the information and support they need
Donate now.**

Cheque, standing order or direct debit: please see the donation form on page 9.

Debit or credit card: visit website www.colostomyuk.org/donate or call us on 0118 939 1537

By text: To donate £5 on your mobile device please text TCUK to 70970. To donate £10 text TCUK to 70191.

Thank you for your support.

Text donations will be processed and administered by the National Funding Scheme (Charity No: 1113471), operating as DONATE. Texts will be charged at your standard network rate. For Terms & Conditions, see www.easydonate.org

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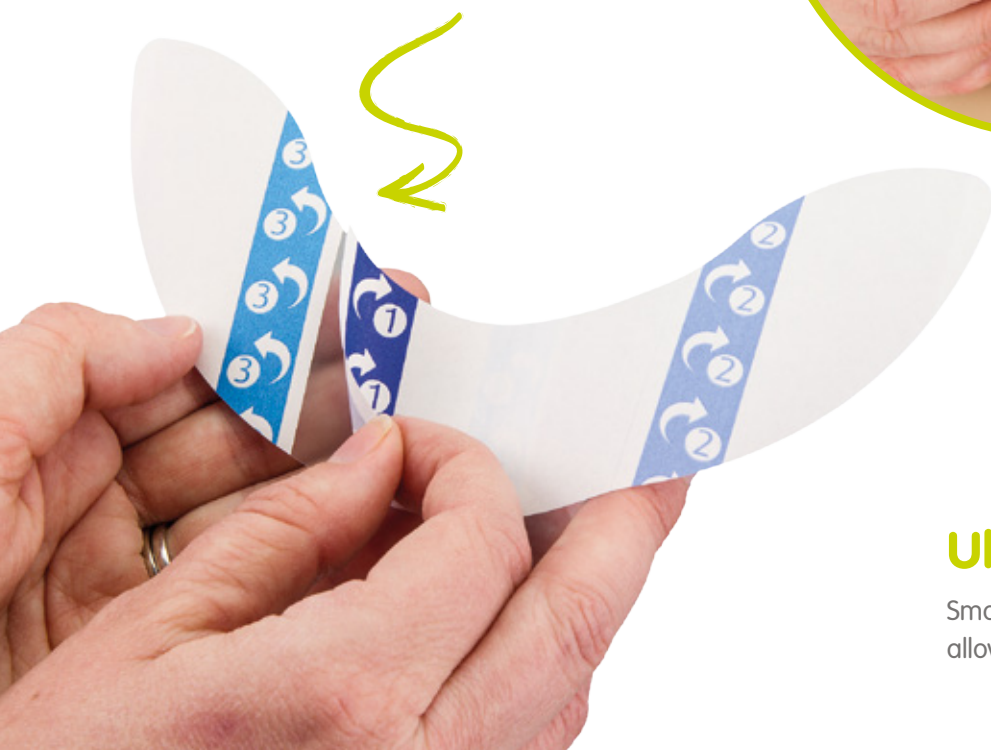
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News from Support Groups across the UK

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.

King's Lynn & District Ostomy Support Group - We're Back!

King's Lynn & District Ostomy Support Group meets quarterly at the Reffley Community Hall in King's Lynn (PE30 3SF).

The Group covers North & West Norfolk, Cambridgeshire and Lincolnshire and is run by colostomy, ileostomy and urostomy patients for patients, their families and friends. Informative talks on health-related matters are given by healthcare professionals and guest speakers. Refreshments and a raffle are provided.

We provide a patient-to-patient forum for members to meet up and support each other and share their tips, to encourage wellbeing and regain self-confidence, in a friendly, informal environment.

We are delighted to announce that meetings will resume in 2022, subject to any applicable government regulations, schedule below:

11th June 2022
3rd September 2022
3rd December 2022

Meetings are 2-4pm, usually on the first Saturday (June 2022 has been moved in recognition of the Platinum Jubilee bank holiday).

We look forward to seeing our friends and group members, both old and new. Come along and join us!

Telephone for further information:

Elsbeth Hardy: 01553 775698
Mary & Chris Thompson:
01406 363756
Mo Ford: 01263 712143
Christine Spicer: 01553 674962

Ashford Stoma Support Group

Face to face meetings are held on the last Thursday of each month. Our venue has recently changed, and we now meet in the War Memorial Hall in Sellindge near Ashford TN25 6JY starting at 2pm.

Meetings include a stoma-related speaker, refreshments, and fund-raising raffle. A local stoma nurse usually attends for any care queries. Partners of ostomates and carers are all welcome.

For further details contact:

Carol Hobbs T:01303 814 014;
David Christian T:07970 220 773;
Maureen Curnow T:07989 773 332

Outlook Staffordshire Ostomy Support Group

Will hold a meeting on Saturday March 12th at 2:30pm at Bradwell Lodge Community Centre, Bradwell Lane, Newcastle-under-Lyme, Staffs, ST5 8PS.

The speaker will be Jeremy Cadman from the charity Blood Bikes, which have played a very important part supporting the NHS during the pandemic.

On Tuesday May 24th at 7.30pm at the same venue, the speaker will be Rebecca Loughhead from the Middleport Pottery.

Please contact Moira Hammond on
07788 402195 for further information.

Wessex Stoma Support Group

We finished 2021 with a flourish, holding our Christmas Craft Fair in November, followed a month later with Christmas dinner at the White Hart Hotel in Salisbury and a trip to the pantomime!

We have a full programme in 2022, please visit our website www.wessex-stoma.co.uk for further details. Meetings take place bimonthly on Saturdays, 2pm – 5pm at the Bob Blandford Scout Hall, Wilton, SP2 0AL.



Open Days

Stevenage Ostomistics

Saturday 26 March 2022 from 10am to 1 pm

Location: The Oval Community Centre, Vardon Road, Stevenage, SG1 5RD

You can talk to manufacturers and distributors and listen to a short talk by a dietitian and stoma care nurse about skin care. Refreshments will be available. We would love to see you there. There is ample free parking and Bus No.2 to St Nicholas departs every 12 minutes from Stevenage bus station and stops at The Oval.

For further information about the day or Stevenage Ostomistics, please contact: please contact: Judy Colston: **01438 354 018** or email **neilcolston@btinternet.com**

Channel Islands

Guernsey

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

Jersey

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

England

Berkshire

WAMS (Windsor, Ascot, Maidenhead & Slough) Stoma Support Group
T: 0118 939 1537
E: wamsstoma@gmail.com

Bristol

Bristol Ostomy Self Support (BOSS)
Janet T: 01934 248 114
Rob T: 0117 966 8021

Buckinghamshire

High Wycombe Stoma Support Group
T: 0800 318965
Milton Keynes Stoma Support Group (MKSSG)
Morag Harvey (Secretary)
E: mkssg.sec@gmail.com
T: 07843 768 386
You Are Not Alone Stoma Support Group - Chesham
Carla T: 07846 354 918
E: carlawright0502@gmail.com

Cambridgeshire

Peterborough Stoma Support Group - Ostomistics
Alan Wright T: 01354 653 290
or 07836 661 102
W: ostomistics.org

Cambridgeshire Ostomy Group

E: cogs-stoma@hotmail.com

Cheshire

Countess of Chester Hospital
Stoma Support Group
Stoma Nurses T: 01244 366 170
Crewe & District South Cheshire Stoma Group
Venue phone number: 01270 560 471
Stockport Support Group
Marion Caulfield T: 0161 320 9400 or 0800 652 6667
Warrington Ostomy Support Group
Louise or Joan T: 01925 454 813

Cleveland

Oops Group
Julie Morrisroe/Carol Younger/
Alison Hall-O'Donnel T: 01287 284 113

Co. Durham

Bishop Auckland Stoma Care Group
Mrs Maureen Davison T: 01388 818 267
E: rdavison816@gmail.com
Darlington Support Group
Margaret Clothier T: 0191 333 2184
Durham Stoma Support Group
Lynn Ridley T: 0191 333 2184

Cornwall

Cornwall & Plymouth Bowel Cancer Support Group
The Secretary T: 01872 241 145
E: cbcsginfo@gmail.com
W: cornwall-bowel-cancer-support-group.co.uk
Lanhydrock Ostomist Group
Mandy Rowe T: 01726 832 642
E: murphy.rowe781@btopenworld.com
Henry Kendall T: 01208 850 986
E: h.kendall380@btinternet.com

Cumbria

Grange Cancer Support Drop in
Marie O'Connor T: 01539 533 279
Stoma Support Groups in North Cumbria
Stoma Care Nurses T: 01228 814 179

Derbyshire

Diverted Local Stoma Support Group
Diana Manning T: 01283 541 311
F.I.S.H.Y.S. (Friendship, Information, Support & Help for Young Ostomates (age 18-45)
E: fishysderbyshire@gmail.com
Mercia Inside Out Stoma Support Group
Sally Chester T: 07500 441 442
Jackie T: 07919 002 612
Gary T: 07779 218 245

Devon

Devon IA
E: devon@iasupport.org
Mid Devon Ostomy Support Group
Janice E: janice234ford@gmail.com
T: 07923 975 051
Plymouth & District Bowel Cancer Support Group
Rita T: 0785 557 1840
E: admin@plmdistbcsq.com

Dorset

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

Essex

Connect
Lin Hart T: 01279 505 273
E: comeconnectwithus@gmail.com

Mid Essex Stoma Support Group
Paul Foulger T: 01245 22
N.E.S.S (North Essex Stoma Support)
Brian Waller T: 01206 540 449
Optimistic Ostomates
Angela Taylor T: 01702 385 510
Redbridge Ostomists Club
Stoma Nurses - Chris / Lisa
T: 020 8970 8321
STEPS - Stoma Essex Patients Support
T: 01268 451 937
E: stepsessex@gmail.com

Hampshire

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

Herefordshire

Herefordshire Stoma Support Group
Carol Steele T: 01432 880 656
E: carolsteeleglo@gmail.com

Hertfordshire

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

Isle of Man

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

Isle of Wight

Optimistics
CNSs Sarah Capon & Sarah Varma
T: 01983 534 009

Kent

Ashford Stoma Support Group
Carol Hobbs
T: 01303 814 014
Treasurer, David Christian
T: 07970 220 773
Secretary, Maureen Curnow
T: 07989 773 332

Dartford Ostomy Group Support (DOGS)
Tracey or John: T: 07779 155 846
T: 07948 974 350
E: dogs-uk@hotmail.com
Dover Stoma Friends Group Support
Carolyn Fullager T: 01304 821 132
GOGS (Gravesend Ostomy Support Group)
Tracey T: 07779 155 846
Helen T: 07710 780 958
Maidstone Stoma Support Group
Judy/Kirsty T: 01622 224 305
MOGS (Medway Ostomy Group Support)
Tracey T: 07779 155 846
Helen T: 07710 780 958
E: mogs-uk@hotmail.co.uk
Sheppey Ostomy Group Support (SOGS)
Shelley T: 07714 734 194
E: sogs-uk@hotmail.com
SWANS Stoma Support Group Swanley
Heather T: 07711 445 312
E: heather601@virginmedia.com
Thanet Stoma Buddies Support Group
Kathy T: 01843 291 825
Tunbridge Wells Stoma Support Group
Cathy Chitty/Mags Donovan
T: 01892 632 323

Lancashire

Kangaroo Klub, Blackpool
Stoma Support Group
Blackpool Teaching Hospital
T: 01253 956 620
E: crc-stomanurses@bfwhospitals.nhs.uk
North Manchester and Bury Stoma Support Group
Julie Meadows (SCN)
T: 0161 720 2815
T: 07774 263 563
Oldham Stoma Support
June Wilde T: 0161 312 5538
Phoenix Bowel Cancer Support Group
Sandra Peet
T: 01772 683 790
W: phoenixgroupbvh.com
E: sandrapeet7@aol.com

Leicestershire

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

Lincolnshire

Grantham Support Group
Bobbie/Rachel T: 01476 464 822

London

Bowel & other Cancer Support Newham
T: 020 8553 5366

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

Merseyside

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

Middlesex

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

Norfolk

James Paget Ostomy Support Group
Sandra Hutchings T: 01502 585 955
Kings Lynn Ostomy Friendship Support Group
T: 01553 775 698
T: 01553 674 962
T: 01553 768 271
STARS (SToma And Reconstructive Surgery social support group)
Sylvia Hughes T: 01263 733 448
E: sylvia.ruth.hughes@gmail.com

Northamptonshire

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

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull T: 07714 479 320
Hexham Ostomy Group
Marie Douglas T: 07941 433 600
Northumberland Cancer Support
E: members@northumberlandcancersupportgroup.co.uk



Nottinghamshire

North Notts Stoma Support Group
Tore and Nicky Norman T: 01773 715 460
Nottingham QMC Stoma Support Group
Robin Ford T: 0115 778 6463
E: hello@nottingham-stoma-support-group.uk
Nottingham Stoma Support
Jenny or Kate T: 0115 962 7736
Mrs B Heath T: 0115 966 3073

Shropshire

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

Somerset

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

Staffordshire

County Stoma Group
Moirra Hammond T: 07788 402 195
E: cm.hammond@ntlworld.com
Outlook The North Staffs Ostomy Support Group
Moirra Hammond T: 07788 402 195
E: cm.hammond@ntlworld.com

Suffolk

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

Surrey

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

Sussex

Brighton & District Support after Stomas (SAS)
Virginia Keefe T: 01273 723 775
Chichester Stoma Support Group
The Stoma Care Team
T: 01243 831 527
The Ostomy Friends Group
Jane Quigley T: 01323 417 400 ext 4552
West Sussex Princess Royal Stoma Support
Tina Walker T: 01444 441 881 ext 8318

Tyne and Wear

Gateshead Stoma Patient and Carer Support Group
Stoma Care Nurses T: 0191 445 3152
NHS Molineux Support Group
John Burchell T: 0191 265 1047
South Tyneside Hospital and Community Stoma Support Group
Jane Barnes, Amanda Logan: stoma care nurses
Sunderland Support Group
Michele Downey T: 07704 949 30
E: micheledowney@outlook.com

Warwickshire

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

West Midlands

Birmingham, IA
Michael Jameson
T: 0121 355 2745 or 07842 555 070
W: birmingham.iasupport.org/events
Coventry Stoma Support
Martin T: 07947 385 643

Wiltshire

Swindon IA
W: swindon-ia.org.uk
Wessex Stoma Support Group
Karen Barryman
T: 01980 590 599 or 07799 863 766
E: info@wessex-stoma.co.uk
W: wessex-stoma.co.uk

Worcestershire

Kidderminster & District Colossus Support Group
Brendon Drew T: 01299 400 843

Yorkshire

Acorn Ostomy Support Group
T: 07580 693 155 (After 6:00pm)
Airedale Stoma Support
Sue Hall T: 01535 646 373
Barnsley Bottoms Up Stoma Support Group
Stoma Nurses T: 01226 432 528
Celia Utley (Chairman) T: 01226 284 262
Behind You (Calderdale & Huddersfield Bowel Cancer Support Group)
Stoma Care Nurses T: 01484 355 062
Bottoms Up (for urology and colorectal cancer patients)
John Whelpton T: 07974 657 146
E: midyorks.bottomsup@gmail.com
Bradford Stoma Support Group
Lisa Hall T: 07552 276 747
Dewsbury & District Stoma Support Group
June T: 07884 003 945
E: dewsssg@gmx.com

Hambleton and Richmondshire Ostomy Support Group
Stoma Care Nurses,
Judith Smith and Mary Hugil
T: 01609 764 620 / 07736 295 131
Harrogate Stoma Support Group
Stoma department office,
Nurse Gill Wilson and Fiona Holtham
T: 01423 555 786
Leeds Bowel Cancer Support Group
Lynda Castle (Colorectal Nurse Specialist)
T: 0113 206 5535
Scarborough Stoma Support Group
Stoma Care Team T: 01723 342 388
Second Chance Ostomy Yorkshire
Jackie Butterworth
E: Secondchanceostomyyorkshire@gmail.com
T: 07544 882 353
W: secondchance-ostomyyorkshire.org
The Hull and East Riding Colostomy Support Group
Pete Smith
T: 07989 565 335 or Pete Rennard
T: 07939 518 642 / 01482 793 966
W: hercosg.org.uk

Northern Ireland

County Antrim

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

County Armagh

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

County Down

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

Londonderry

Causeway Support Group
Mary Kane T: 028 7034 6264

Scotland

Ayrshire

Ayrshire & Arran Stoma Support Group
Hugh Strathearn T: 07837 464 376

Stoma Care And Recovery (SCAR)
Maggie T: 01294 271 060/ 0781 773 6147
E: maggie13@sky.com or Rhona
T: 01294 557 478

Fife

Fife Ostomy Support Group
Ishbel Barr T: 01592 772 200

Lanarkshire

Glasgow Stoma Support Group
Morag Sinclair T: 0141 779 1322
Jackie McChesney T: 01505 324 052

Moray

Moray Ostomates Support Group
Meggie T: 01343 552 449
Kathleen T: 07789 684 285

Scottish Borders

Stoma Support Group
Nancy Fraser E: nancyfraser@talktalk.net
T: 01450 374 012
Fiona Gentleman E: r.gentleman@sky.com
T: 01450 371 063

West Lothian

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

Wales

Aberystwyth

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

Bridgend

Bridgend Ostomy Patients Support Group
E: bridgend.ostomy@gmail.com

Carmarthenshire

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

Conwy

North Wales Ostomy Support Group
Hazel T: 07976 817 246
Lesley T: 07828 837 325

Gwent

Cwmbran Ostomy Support Group (COSG)
Philippa Lewis T: 01633 791 339 or
07504 713 069

Mid Glamorgan

C.A.S.S Colorectal and Stoma Support Group
Chairperson T: 01685 877 144

Pembrokeshire

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

Powys

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

Rhondda Cynon Taf

Royal Glamorgan Stoma Care Support Group
Domenica Lear T: 01443 443 053

Swansea

Swansea Ostomy Self Help Group
Glynis Jenkins T: 01792 418 245

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Jennie H.



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