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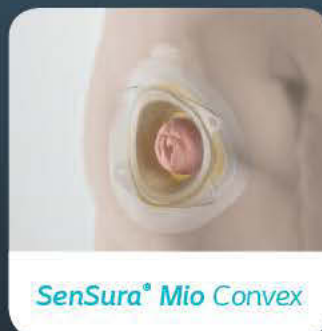
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Cover picture

Colostomy UK office team and volunteers at the launch of the 50K Challenge. See pages 26–27 for more details.

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April already, it hardly seems possible. Even though Easter was only a week or so ago, the memories have started to fade. Possibly it's age? Neither of us are spring chickens...but we prefer to think that the speed with which this year is passing has more to do with how busy we are at **Colostomy UK**.

We have lots of exciting things on the go and this includes our new 50K Challenge, which you can read more about on pages 26 and 27. As you'll see, it's all about encouraging people to be active, while raising funds for **Colostomy UK**. Everybody knows how important exercise is to our wellbeing, so we encourage you to get involved. If you do, you'll be joining the office team, trustees and volunteers. We aren't going to spoil the fun by saying what we have planned, but rest assured you will hear about it in the months ahead! As the 50K Challenge draws to an end in October, World Ostomy Day is next on the agenda. This triennial event aims to raise awareness of the needs and aspirations of ostomates. We are currently in talks with IA and Urostomy Association to decide how we can best work together to support the day. For those with memories long enough, you'll know that this is something of a déjà vu moment, because it was our three charities that originally organised and co-ordinated the very first World Ostomy Day 26 years ago. We will update you on our plans in due course, but in the meantime look out for the hashtag **#speakingoutchangeslives** on social media, which has been chosen to promote and talk about the day.

You can find out more about what we've been up to and what we have planned in the pages ahead. We're confident that there is something for everyone in this issue of Tidings. In addition to all the usual features we have a topical piece on waste and NHS expenditure. This taps into recent reports in the media about plastics and speculates about what this might mean for ostomates in the future. Our article about travel and airports provides some useful up-to-date information and advice for all of you planning an overseas holiday this year. We have two real lives stories. One from Garry, who at age 40 had a stoma formed due to diverticulitis. As you'll see it's an inspiring read about a journey that led Garry to change career. In the process he has also become a volunteer for **Colostomy UK**. Our other story is from Rita, who gives a very different view on stoma surgery...this time from the perspective of the patient's partner.

Finally, in an article called 'Just how important are charity cake sales', Richard Biddle says a long overdue thank you to those who organise fundraising events and make donations. As he says, it's because of such people that we can produce Tidings and do all the other things that we do to support and empower ostomates across the country.

With our best wishes.



Libby

Libby Herbert
General Manager



Sarah

Sarah Squire
Trustee, Colostomate
and Volunteer

Donating to Colostomy UK

An annual donation of £20 (or whatever you can afford) allows us to produce *Tidings* and to continue our vital work, supporting, and empowering ostomates – see page 43 for donation form.

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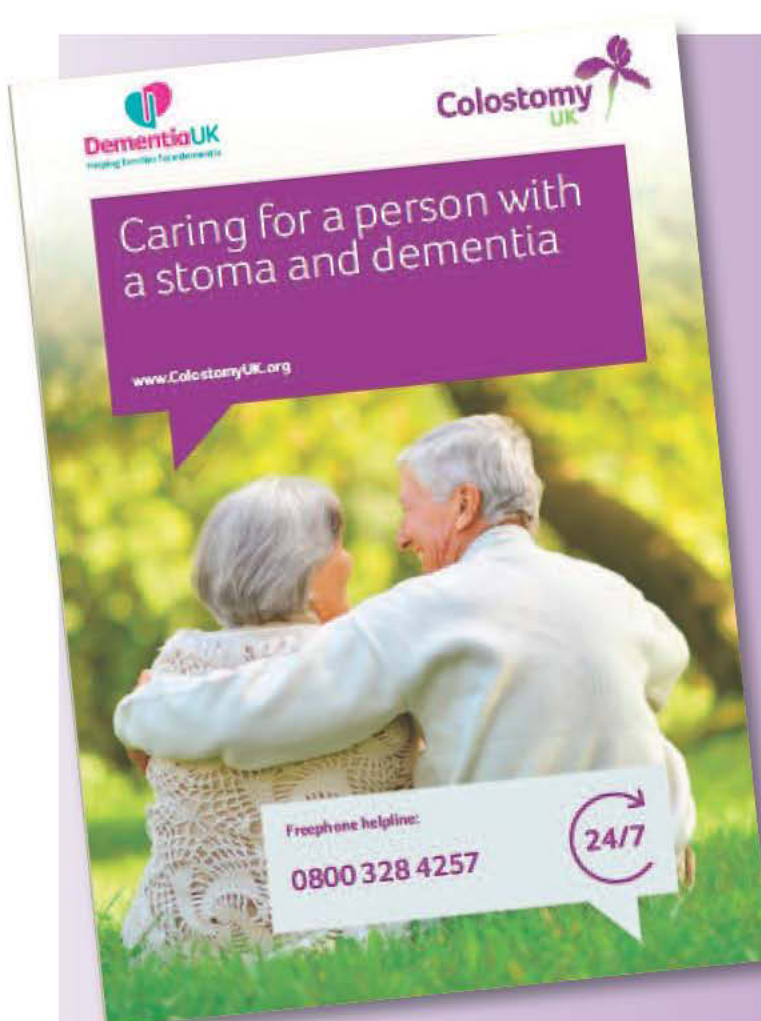
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You can donate via our website www.ColostomyUK.org/donate or by calling us on 0118 939 1537

Bulletin Board



Partnering with Dementia UK

We have partnered with Dementia UK to launch a new booklet ***Caring for a person with a stoma and dementia***. This is aimed at healthcare professionals and carers more generally. If you would like a copy or know of someone that would, please call us on **0118 939 1537**, email info@ColostomyUK.org or visit our website. www.ColostomyUK.org



Salisbury becomes first stoma friendly city

Salisbury City Council have been working closely with The Wessex Stoma Support Group, **Colostomy UK** and Crohn's & Colitis to become the first stoma friendly city in the UK.

Council owned accessible public conveniences including the Market Place, Guildhall and Coach Station now have a hook, shelf, bin and 'Not all disabilities are visible' signage.

Cllr Jo Broom from the City Council said: "The Council understands that it is important to make these additions to our accessible toilets in the City Centre. We want to thank the organisations involved for bringing this to our attention and providing us with the support to achieve stoma friendly toilets in Salisbury."

We are Buzz Connect's charity of the year



Buzz Connect help build stronger business communities across West Berkshire and North Hampshire. They provide organisations of all sizes with the opportunity to: develop mutually supportive relationships; build a local supply chain; access advice and guidance from local businesses and business experts; enhance knowledge and skills by attending learning activities and events; share knowledge and experience with other businesses and business leaders.

They have chosen **Colostomy UK** as their Charity of the year for 2018 and we look forward to partnering with them throughout the year. ■

01635 200 006

info@buzz-connect.co.uk – <https://www.buzz-connect.co.uk/>

Important News: Stoma Aid Project

Since its launch in January 2016, Stoma Aid has dispatched over 2,500,000 units of stock to the developing world. By working in partnership with other charities we have managed to reach ostomates all over the globe, including: Ethiopia, Kenya, Kosovo, Pakistan, Mauritius, Moldova, Nepal and Syria.

Unfortunately, as the project has grown, so too has the volume of unsuitable donations. Despite our efforts to communicate what was acceptable, we have continued to receive everything from non-ostomy medical supplies to clothes and general bric-a-brac. This has greatly increased the time needed to sort and pack consignments of ostomy supplies and we have incurred costs

disposing of items we cannot use. As a consequence, we have had to take the sad decision of closing Stoma Aid with immediate effect, as we do not have the infrastructure to support the project.

We would like to thank Frank, Pat, Crisi and David for all their hard work in running Stoma Aid and everyone who has donated supplies. We are continuing to offer support where we can to charities including **Jacob's Well Appeal** and **Hand in Hand Syria**, as they continue to aid ostomates in need in developing countries. If you want to donate any stoma supplies please send them to Jacob's Well Appeal, Swinemoor Lane, Beverley, East Yorkshire HU17 0JX, Tel: **01482 881162**.



Working with airports

Last year we received many complaints from ostomates travelling through Manchester Airport. Since then we have been working with Manchester Airport Group (MAG) and Outsourced Client Solutions (OCS), to train security and customer service staff on stomas and how to respond when meeting a traveller with one. We've already seen a large drop in complaints and look forward to working with other airports across the UK, including London Heathrow.

MAG have given us some useful tips for ostomates so you can ensure that your journey through the airport runs smoothly.

More information on airports can be found on pages 11–12. ■

Remember:

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

Blue Badge consultation

The government is currently seeking consultation on the Blue Badge Scheme. The scheme plays a vital role in allowing 2.4 million disabled people in England to maintain their independence through special national parking concessions. Although the current rules embrace all conditions, physical or otherwise, it has become clear to the government that the regulations and guidance are not clearly understood by local authorities. As a result, people with hidden disabilities, such as a stoma, can find it difficult to get a badge, even though their condition warrants them having one.

The proposition is that the scheme should be about enabling people to make journeys that would otherwise be extremely difficult and to focus on the journey rather than just the physical act of walking.

Colostomy UK welcomes this consultation. In our view, having a stoma should not lead to an automatic entitlement to a blue badge. Instead, we would prefer to see a system whereby applications for badges are judged individually, on their own merits. This is because every ostomate is different. For some, their stoma presents no barriers to living a full and active life. Others though, are less fortunate. For these people, a blue badge could be a life changer, heralding the return of confidence and independence, and empowering them to do things that were previously difficult or impossible.

Colostomy UK encourages its supporters to respond to the consultation: <https://www.gov.uk/government/consultations/blue-badge-disabled-parking-scheme-eligibility-review/blue-badge-scheme-consultation-on-eligibility#how-to-respond> ■

National Key Scheme – changes to RADAR keys

The National Key Scheme (NKS) offers disabled people independent access to locked public toilets around the country.

Toilets fitted with NKS locks can now be found in shopping centres, pubs, cafés, department stores, bus and train stations and many other locations in most parts of the country.

RADAR are now phasing out the sale of the steel keys, but don't worry the keys will still work. Radar are now selling solid brass keys which work much more reliably. As soon as our stock of the steel keys runs out we will start selling the brass keys. ■



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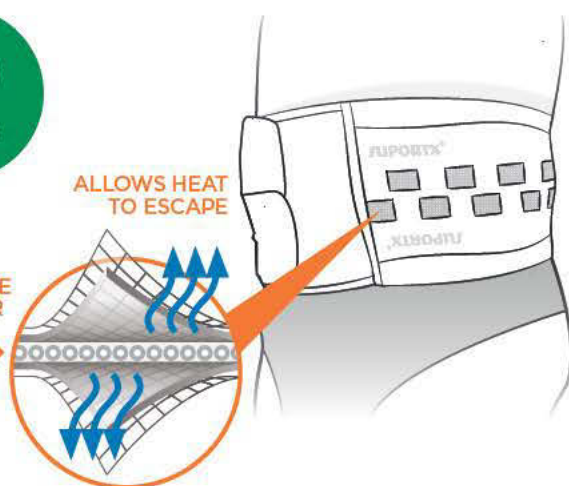


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'Have bag, can travel'

Richard Biddle

Spring is in the air and all over the country people have begun the countdown to their summer holidays. The sense of anticipation is palpable. Perhaps it's just me, but I'm sure I've noticed phrases like 'I need a break' and 'where are you off to this year?' creeping into conversations. At **Colostomy UK** we know that ostomates are just as keen to 'top-up the tan' as anyone else. In 2017 we sent out over 3,500 Travel advice booklets and responded to nearly 700 travel-related enquiries. Judging by last year's calendar competition our readers certainly like to visit far flung places too. We had pictures submitted from Australia and Israel, as well as Norway, Spain and Hawaii.

We also know that air travel and foreign holidays can be a source of concern for people with stomas. Common worries centre around transit through the airport (body scanners, searches, baggage allowances) and stoma management

(foreign diet, output, running out of supplies). Sadly, as last year's holiday season got underway, a much higher than normal number of ostomates contacted us to complain about the poor treatment they had received at UK airports

(particularly Manchester). The emergence of this trend was all the more worrying coming, as it did, on the back of a publication by the Civil Aviation Authority (December 2016) which stated clearly

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L-R: Giovanni Cinque, Marc Van Der Laan – Terminal 2 security manager, Caroline McWhirter – Security Duty Manager, Richard Biddle, Libby Herbert

and unambiguously that people with hidden disabilities and conditions should enjoy the same opportunities for air travel as everybody else.

As advocates for ostomates in general, we didn't feel it was enough just to support the people who contacted us. In our view the volume of complaints pointed to a wider problem. Further investigation revealed that a lack of awareness amongst airport staff about stomas was the common denominator in all the cases. Having worked with airports in the past on similar issues, it came as no surprise that the head of security for Terminal 2 at Manchester Airport was happy to co-operate with us in finding a solution. As 2017 drew to a close there was a flurry of activity. This saw us: visiting Manchester Airport; being invited to and attending their Accessibility Expo and subsequently becoming members of their Accessibility Forum; hosting airport security staff at our offices in Reading; being invited to work with Outsourced Client Solutions (OCS), who provide customer service staff for many of the UK's airports.

The spirit of these meetings was one of positive collaboration and much was achieved. As I write this article, we are in the process of putting together teaching resources that will be incorporated into the training programmes for all new and



existing airport staff at Manchester. The airport has also been able to amend some of its standard operating procedures to better take account of the needs of ostomates. As Manchester Airport Group also owns Stansted, East Midlands and Bournemouth airports, we expect a broader roll-out in due course. Word of what we are doing has obviously started to spread, because in January we were contacted by Heathrow Airport and asked to join their Air Transport Group. Of course, there will always be instances where people have a negative experience on their journey through an airport. But, by raising awareness and by having input into the training of customer-facing staff, we hope to halt last year's trend in its tracks.

We have also learned much by working with the organisations mentioned above. It is very clear that although they want to make transit through UK airports as smooth as possible

they have to balance the needs of travellers against a demanding and ever-changing security threat. As a consequence, no-one is exempt from the various security processes in place. As security staff advised us, terrorists and criminals will use everything from shoes to medical appliances, in order to disguise and hide illegal items. There is, however, much that individual ostomates can do to make their airport and air travel experience positive. The one key message I have taken from our discussions so far, is that people need to take responsibility too and the best way they can do this is by **being prepared**. This means doing things like contacting the airport well in advance if you have additional needs. The checklist in our travel booklet and the hints and tips in this issue's Bulletin Board (see page 9), give further valuable advice on preparing for travel. But being prepared goes further than this... it also means having realistic expectations and understanding that, as an ostomate, you are still subject to the same security checks as everyone else. Given the fluid nature of this story, any fresh advice we receive will initially be posted on our website. So don't forget to check it a week or so before you travel! ■





Spotlight on a rare condition

Specialist Nurse Advisor, Sally Wright was contacted on the Amcare Help line by a patient's relative. The relative was enquiring about help for his father who had had a colostomy for many years, but was currently struggling with the skin around it, which was extremely sore.

During the call we talked about what was happening with the stoma, if there had been any leaks, what was the output like, how long the skin had been sore and what products were being used at present. I asked if the family could take a photo and email it to me so I could see exactly what was happening and assess their father's skin.

When I saw the photo I was shocked by how sore the skin was looking. There were very specific and defined punched out areas rather than the generalized skin soreness I normally see. No wonder he was in so much discomfort.

I immediately contacted the patient's GP and, with the GP's approval, swiftly started some topical steroid treatment. I also asked Mandy Smart (Amcare Community Nurse Specialist) to provide a home visit for

additional support so that she could fully assess his skin for any improvement or deterioration. In the meantime, the GP agreed to refer this gentleman to the Dermatology Department at his local hospital. He later commenced prescribed oral steroid medication as the skin was not improving with cream alone. Mandy kindly visited the family to help show them how to apply the cream and dressings beneath the flange they were using. The steroid cream needs to be applied sparingly as it can affect the adherence of the flange to the skin.

I also liaised with the hospital stoma care nurse (SCN) team at their local hospital as they hadn't seen him for a while. I felt that with all our involvement, he would feel better supported. The SCN team also managed to arrange a review with his surgeon.

After a few weeks of treatment the skin had dramatically improved.



The patient's son-in-law phoned me a few weeks later following the Dermatology appointment, to confirm that the biopsy they had taken confirmed it to be Pyoderma Gangrenosum, as I had originally suspected. Pyoderma Gangrenosum (PG) is one of the less common, but more challenging issues affecting peristomal skin. We had used all the correct treatments and therefore the skin had responded well.

The GP and Dermatologist were now aware of what they were treating if the skin were to flare again in the future... but for now, it meant that we could go back to the basics of finding a flange and pouch he felt comfortable with.

Both Mandy and I were thrilled to receive a signed patient testimonial from the family who were grateful of our help and support.



Sally Wright
Specialist Nurse Advisor

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Trash talk

Richard Biddle

Soon after I got married, my wife's grandmother gave us some advice about bed sheets. To save money, she suggested that when they wore thin in the middle, we cut them in half, flip them over and stitch them back together again. I'm sure you can guess the reaction she got from a couple of newlyweds! But, as my mum said later: "that's the war generation for you". Now, nearly thirty years on, I've come to realise that old granny Fox and me had more in common than I thought. Just like her, I have grown to hate waste. It pains me that, no matter how hard I try, I always seem to let food in the fridge pass its sell by date and end up throwing it away.

As a society we are obsessed with waste (in all its forms) and the cost of waste too. Seemingly every day there are reports of bin men going on strike and local councils amending the frequency of refuse collections. More recently the focus has been on discarded plastic polluting the oceans. If you've kept up-to-date with this story, then you'll know that the statistics are frightening. Green Peace estimates that 12 million tonnes of plastic waste enter the planet's oceans each year, with a single plastic bottle taking over 450 years to decay.

The reasons for disliking waste are many. Take my food example, put bluntly it is the equivalent of earning money just to throw

it down the drain. But, of course, it goes wider than this. There is also an environmental cost to my loose grip on domestic 'stock control'. Energy was wasted producing the food and transporting it to the shop. The fuel expended in the process released pollutants into the atmosphere. The same was repeated when I drove to and from the shop, all to buy food that I was going to throw away. Then there was the packaging. This is probably sitting in landfill now, unless it hasn't already blown away and ended up in one of our rivers, on its way to the sea.

While I'm sure that you can sympathise with my problems of keeping tabs on sell by dates, you would be forgiven for thinking

what, specifically, does all this have to do with ostomates? Well let me tell you. Back in December last year myself and Jo McKenzie attended a stoma open day at Tolworth Hospital in Kingston. One of the talks we listened to was given by a senior prescribing advisor from Kingston Clinical Commissioning Group. She explained that prescribing stoma care products remains a significant cost expenditure for the NHS and also an area which has been identified as causing a great deal of waste. The reasons cited for this were many. On the one hand there were issues with over prescribing and over ordering. On the other, things such as changes to stoma size or reversal surgery

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CONTINUED FROM PAGE 15, COLUMN 3

lead to patients (through no fault of their own) building up surplus supplies. The impact is two-fold. Firstly, the money wasted could have been used elsewhere in

the NHS. Secondly, as the NHS cannot accept returns, unused stoma products tend to end up on landfill. This is because with their plastic content they cannot be recycled.

Changes are therefore afoot. While it was evident from the talk that clinical commissioning groups remain committed to ensuring that patients receive products to give them the best quality of life, it was also clear that they are actively exploring ways to save money and reduce waste. Reducing the number of stoma bags included per box was one of the possibilities mentioned, as this might go some way towards addressing the issue of leftover supplies following reversal surgery. There are also ongoing discussions with GPs who, it seems, are likely to be encouraged to ask for their patients to have a stoma review before prescribing new accessories. As you can imagine, the talk led to some lively discussion afterwards, in which ostomates expressed a range of concerns and also shared a number of prescribing horror stories. Although at the moment, we can do little else but await developments, few would argue with the rationale behind reducing waste in the NHS. And, given the government's recent announcement of a 25-year environmental plan, which includes a war on plastic, one might speculate that, in time, the materials used to make stoma bags will change too. In fact, we are starting to see the beginnings of change in this direction. While CliniMed's Aura flushable bag range has some very obvious lifestyle benefits, it is notable that the product contains biodegradable materials. As they say, necessity is the mother of innovation.

We will keep you up-to-date with any news on waste via our website, social media and future editions of *Tidings*. ■



"It's his Spring idea for recycling his spare bags!"





Active Ostomates

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

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

Do you play Rugby League?

Colostomy UK are looking for ostomates who would like to, or already play Rugby League, for an exciting new project. If that sounds like you please get in touch with Giovanni Cinque at **0118 939 1537** or on **Giovanni.Cinque@ColostomyUK.org**

Stress Free outdoors

Colostomy UK are delighted to announce that we have teamed up with Stress Free Outdoors to offer a great deal to ostomates and their families who would like to take advantage of the 'Great Outdoors'.

Based in Cornwall, Stress free outdoors offer a range of guided walks, camping trips and bush craft activities, with events that last just a couple of hours through to weekend adventures. Prices start at as little as £20 per person.



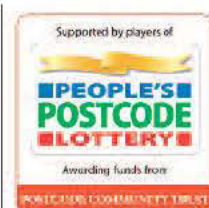
Run by ostomate Al Edwards, Stress Free Outdoors is a social enterprise that aims to make a difference for people living with a stoma and/or inflammatory bowel disease, and their families.

Colostomy UK and Stress Free Outdoors are offering 33% off all bookings. To take advantage of this offer and for more information visit www.stressfreeoutdoors.co.uk. To qualify for the discount just enter the code **colostomyuk** at checkout (please note the code needs to be entered in lowercase).

Funding support for 'Active ostomates'



NATIONAL LOTTERY FUNDED



In December we were thrilled to hear the news that we had been awarded funding from both The Big Lottery Fund and the Postcode Community Trust. Both grants will support the continued expansion of 'Active ostomates' through our chair yoga programme and by allowing us to offer tasters in a number of other sports and activities.

Our chair yoga programme currently runs in partnership with the East Berkshire Ostomy Club, Stevenage Ostomistics, Sheppey Ostomy Group Support and The Milton Keynes Stoma Association.

CONTINUED ON PAGE 19, COLUMN 1



NEW



Recognising Salts research
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Our extremely popular seals are now even kinder to skin! Salts Mouldable Seals with Aloe mould easily to the exact size and shape of your stoma, creating a customised, comfortable leak-resistant seal.

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Salts Mouldable Seals with Aloe is just one of the products in our skincare range. Discover more at www.salts.co.uk





CONTINUED FROM PAGE 17, COLUMN 3

If you would like further information on chair yoga or are part of a support group and would like to join our 'Active ostomates' programme please call us on **0118 939 1537** or email Giovanni.Cinque@ColostomyUK.org

Are you an Active ostomate?



Each issue we intend to profile one of our supporters who has taken up being active after surgery. Kath McClinton is the first of our 'Team Colostomy UK' ambassadors to feature. Here is Kath's story:

Now 60, I've always been an active person. Walking, running, skiing and swimming are my things. When I was first diagnosed with bowel cancer and I heard the doctor say: "You have a large malignant tumour in your rectum". I can remember thinking: "I wonder if I'll be able to swim tomorrow?". As it turned out I couldn't. And months of chemo and radiotherapy, followed by major surgery resulting in a permanent ileostomy, didn't do much to celebrate my intense relationship with the water either. But having been active undoubtedly helped me in my recovery and when, some four months after surgery I decided to, literally, put a toe in the water, I felt for the first time that there was a way forward.

In the three years since, I've resumed running, skiing and, most importantly to me, swimming in pools and open water. A year after diagnosis I happily returned to my

swimming club. I've had to relearn some skills and rebuild my swimming muscles, but the water is the one place where, in the rhythm of a long swim, I feel closest to the old me. I'm not the same. It has been difficult at times. But I know now that the only limits on what I can accomplish are those in my head.

I'm very proud to be part of Team Colostomy UK and wear my swim hat with pride.

Modified sports



The last few years have seen most of the UK's major sports introduce modified versions of many of the traditional sports we know and love.

Modified sports can take many forms but are generally designed to provide an introductory and/or more accessible offering to various groups such as children, mature-age participants, persons with medical conditions, time-poor people, or for those who are simply looking for new physical activity and social engagement opportunities.

Modified sports can also provide an opportunity to develop general movement skills and basic techniques. Modified equipment, facilities, and rules are commonly used because of the developmental stage (age, physical size, motor skill proficiency) of participants.

To find out more or search for your nearest club visit the following links

Masters Rugby League

http://www.rugby-league.com/leagues-competitions/masters_rugby_league

Walking Football www.thewfa.co.uk and www.walkingfootballunited.co.uk



Walking Netball

www.englandnetball.co.uk/my-game/walking-netball

Walking Rugby

www.better.org.uk/walking-rugby

Last man stands Cricket

www.lastmanstands.com

Touch Tennis www.touchtennis.com/gb

Making a splash

March saw us hold two 'Make a splash' swimming taster sessions at the Sheppey Leisure Centre in Sheerness.

The 'ostomate-only' sessions allowed people to turn up and have a swim on their own or with friends and feel firsthand the health benefits of swimming.

Afterwards everyone had the chance to mix over a well earned cup of tea, find out more about Active ostomates and also learn how they could get involved in swimming more regularly.

If you're interested in visiting your local pool or taking up swimming for the first time why not visit www.swimming.org

Help and advice from Colostomy UK

Our *Active ostomates: sport and fitness after stoma surgery* booklet is full of great tips on exercises you can try at home plus advice and links to loads of sports and activities that you can safely take part in.

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

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

We deliver...



The building blocks of our **home delivery service** is to put you first. We deliver all brands of stoma, continence and accessory products discreetly to your door and with text message delivery updates we work hard to ensure our service supports you.

We offer personalised pouch cutting and a wide choice of complimentary items. Our friendly customer service team is available Monday to Friday, 8am – 9pm and has over 20 years experience in providing expert product advice from all manufacturers.

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To find out more about joining the
SecuriCare home delivery service visit
www.securicaremedical.co.uk

or call us on
0800 585 125



Dear Nurse

**Julie Rust RGN. Dip, N. MSc.
Clinical Nurse Specialist
Stoma/Colorectal
Royal Stoke University Hospital
University Hospitals of
North Midlands NHS Trust**



Julie Rust became *Tidings* Nurse in December 2004. She has answered readers' letters and e-mails in every issue which has been published since then. We look forward to many more years of publishing her very sound advice.

Your medical questions about stoma care management are always welcome and important to us.

Q: *I would be grateful for your advice. I am 75 years old and have been a T8/9 paraplegic for 50 years. I had a left hemicolectomy at the end of 2007 to excise what proved to be a T4 tumour. The only point arising from the procedure which might be relevant to my enquiry is that through a pain haze I vaguely remember the surgeon saying that he had cut my rectum "high". I assume that by that he meant he left me the largest rectal stump possible, but if any further explanation was forthcoming, I don't remember it.*

Touch wood, I have had few problems since the procedure was performed, but I have what appears to be a problem with what remains of my rectum. From relatively soon after the operation I started to get a lot of pain and discomfort that manifested itself as coming from my anus and which greatly increased the muscle spasms from

which I suffer. However, using a glycerin suppository every 4–6 weeks to remove a waxy deposit that had accumulated greatly relieved the problem. I needed to do this for a couple of years until I suddenly found that I was spontaneously producing a colourless, virtually odourless, lubricating gel-like exudate every few days. While I produced this I was virtually free of the pain and extra spasms I had suffered previously. Unfortunately this phase only lasted 2–3 years and the situation reverted to what it had been previously with one difference. I still use a glycerin suppository periodically, but rather than the waxy deposit this produced previously, it now produces a reddish-brown, slightly malodorous exudate. Unfortunately this seldom has much effect on the pain and spasms which have been getting worse over the past 1–2 years.

A previous colonoscopy report referred to "inflammation in my rectum" and some antibiotics prescribed for urinary infections induce periods of near complete remission of the anal pain and spasms, suggesting that infection is playing a part. I won't go into detail about the adverse impact of the pain and spasms on my life other than to say, for example, that the increases in the latter put me at risk of falling every time I get out of bed.

Neither my GP nor the consultant to whose list I have recently been transferred seem particularly interested. Without actually saying so they seem to be saying I will have to live with it although it is nigh impossible to do so. In the circumstances I was wondering if you could suggest anything.

AK

CONTINUED ON PAGE 22, COLUMN 1

CONTINUED FROM PAGE 21, COLUMN 3

A: Having your rectal stump left in situ can lead to all of the problems you describe and I do know people who regularly use Glycerine Suppositories to clear the mucous from the rectum. However you can on occasion get an infection here and Antibiotics may be used for this specific purpose. There is also something called defunctioned colitis which is an inflammatory response in a piece of bowel which is no longer in use, ie defunctioned and this could be your problem. It is easily treated with steroidal suppositories/enemas to reduce the inflammation. It would be worth seeing your consultant to discuss this to see if this is the cause of your issues and if so to see if they will prescribe a course of steroid based suppositories or enemas. I hope you get this sorted as it can be a very irritating problem which hopefully can be easily rectified.

Q: *I wonder if you can give some advice. I have an ileostomy and I've got to have a Barium meal. As I am aware from friends, this can really thicken output. Is there anything I can do to prevent a blockage? I am worried this might happen even though my output is loose and I use thickeners*

DK

A: I would advise you to drink plenty of fluids post procedure and if the output starts to become problematic to speak to your Stoma Care Nurse. Laxatives with ileostomy are not advised without monitoring as they can cause an extremely loose output, dehydration and potential for kidney problems. If you are still concerned contact the department where you are having the procedure or your stoma care nurse prior to it being done.

Q: *I read with interest your letters page and wondered if you could give an answer to my query?*

I had a perforated diverticulum (hole in the bowel) operation back in 2003. Because of this I was left with a colostomy on the left side. Unfortunately, a reversal was ruled out as the Professor who performed the operation retired. Anyway, over the years everything was fine until about four years ago when I developed granulomas around the outside of the stoma and have frequent bleeding problems.

I have seen the doctor, the stoma nurse and the surgical team that deal with this type of problem. I have also had three Colonoscopies and at the latest (August 2017) samples were taken from the inside of the bowel. I have not heard any results from this yet. However, I have taken videos via mobile phone to prove that the bleeding is also coming from the inside of the stoma which the consultants have seen. However, they say there is not a lot they can do and just keep using pads to stop the bleeding.

I was also given a treatment (Avoca Caustic Pencil) which I thought was to remove the granulomas? It hasn't so far. I have often wondered if there was a spray/paste or a pad that would help with stopping bleeding. At the age of 67 the consultants seem to be reluctant to do too much surgical work now and I'm left to get on with it. Is there any suggestion that you may have to help with this? I read the article in the Autumn editing of Tidings Pages 30-31 and also wondered if Ferrous Fumarate I take would cause problems. I'm also on Metformin and Ramipril small doses.

RR

A: It would be worth contacting your consultant to get the results of the colonoscopy as this may have identified the cause of the bleeding or at least

ruled out any problems causing it, especially if it has been identified that the bleeding is from inside of the bowel rather than surface bleeding alone. With regards to the granulomas the most common treatment is the use of 75% Silver Nitrate but if this has not worked for you there are other treatment options including Haelan Tape, liquid nitrogen treatment and finally surgery which can all help to remove the granulomas. I would firstly ask to see the stoma care nurse to see if they can offer treatment for the granulomas or if they can advise on who to see for more advanced treatment options. Hopefully with the results of the colonoscopy you can be reassured with regards to the bleeding and a treatment plan can be identified to treat the granulomas. ■

If you have a general medical question or a query about stoma management:

E-mail:
editor@ColostomyUK.org

or write to:
**The Editor
Colostomy UK
Enterprise House
95 London Street
Reading
Berkshire
RG1 4QA**

Your questions will be passed on to Julie Rust. Although Julie is not able to reply directly to you, her answers will be published in the next issue of Tidings.

Julie's answers to questions about issues such as leakage, rectal discharge, or managing hernias or retracted stomas etc. may not only help you, but may also provide advice and reassurance to others experiencing a similar problem.



Photo ID Card

The **Colostomy UK** photo ID card is proving very popular as it can be useful if challenged when entering or exiting accessible toilet facilities.

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

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

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

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

Allow 10–14 days for delivery.

Previously issued cards will still be valid.

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

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

(If you have any queries or would like to make a credit card payment, please contact the admin team at the **Colostomy UK** office via the following methods: Telephone: **0118 939 1537** or Email: info@ColostomyUK.org)



National Key Scheme - Key and photo ID card purchase

Title: _____

Name: _____

Address: _____

Postcode: _____

Tel: _____

Email: _____

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

Signature of self or carer: _____

Please **tick** as appropriate:

☐ I would like to receive a **key** for a charge of **£3.50** (including postage and packing).

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

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

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

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

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Readers' writes

Dear Editor

15 months after Lidl applied to build a store in Loughborough, the Council approved it just before Christmas. It will have toilet facilities (much needed) and I have contacted them to see if there is a disabled toilet that there will be facilities for 'colostomates' in the store. I said that if they wanted any advice to contact **Colostomy UK** and also suggested that could they provide the facilities in any of their other stores that have disabled facilities. I am waiting for a response. I have just received the Winter edition of

Tidings and I see that Sainsbury's are going to do the same, although I think they will have difficulties with their Loughborough store, but we will see. I hope I haven't overstepped the mark by suggesting Lidl contact you.

Best Regards
Peter Bruce

***Editor's note:** Visit our website to read more about our campaign. As Peter suggests in his letter, we can give organisations advice on making their toilets 'stoma friendly'.*

Dear Editor

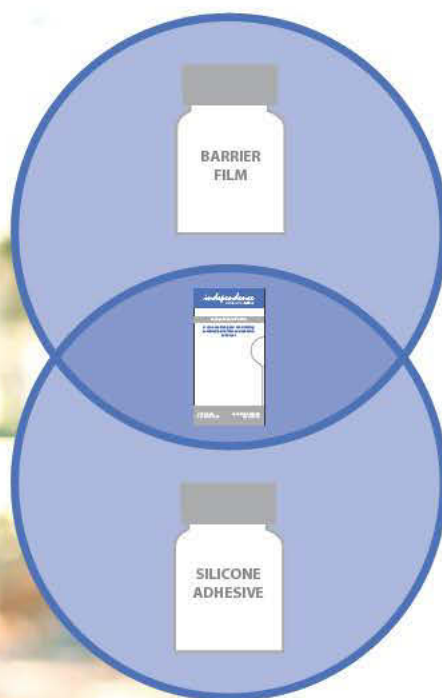
Fortunately, my stoma behaves most of the time and after a night climb of Ben Nevis to raise funds for Macmillan Cancer Support, I thanked it for not letting me down during the ascent and descent.

However, on the long bus journey back from Fort William there was a minor explosion with my appliance becoming detached and a major leakage.

There was nothing for it but to brazen it out until the bus reached Glasgow where

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I was able to shower and change before continuing my journey.

It was with a wry smile that I was aware of neighbouring passengers quietly moving away to other seats!

HT

Editors note: Visit our website *Leaks happen from time-to-time. But if you are having persistent problems with leakage then you should consult your stoma care nurse.*

Dear Editor

I have had a colostomy for 23 years and after such a long time "I thought I knew it all". That was until I had a very bad sinus attack that resulted in constant running catarrh. After several days I found that I was getting the usual pain in the backside that I normally associated with a blocked anal discharge (nasty and painful). A few days later, I

found that the stools in my bag were almost solid.

At that time I did not connect the sinus problem with my colostomy problem, so I started a web search for information and found your web page and 24/7 Helpline. The gentleman I spoke to was most helpful and suggested the root of my colostomy problem may be dehydration from my sinus discharge. As soon as he said it, the penny dropped, and, after a few days of heavy drinking my colostomy situation returned to normal.

It was logical when you think about it, but of course you do not think clearly when you are unwell and in pain. Please accept my sincere thanks to all concerned at Colostomy UK and it is most comforting and reassuring to know that practical help is always available, especially when you need it most.

Philip Stanley

Letters to the editor are welcome, but we also crave your stories and anecdotes. And then there's hints and tips for ostomates, plus concerns you have to raise or burning issues you want to air, we want these too... and so do our readers. Don't worry if writing isn't your thing, because we can do this with you. Just drop us a line, send as an e-mail, or give us a call and we will take it from there.

E-mail to:

editor@ColostomyUK.org

or a letter to:

The Editor
Colostomy UK
Enterprise House,
95 London Street
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50K CHALLENGE

Join the Colostomy UK 50K Challenge today!

Get active, spread the word that people with stomas can do anything and raise funds to help us make a difference for people with a stoma in the UK.

Over a six-month period (April 9–31 October) we want you to run, walk, climb, swim, cycle, skate, crawl or jog any number of metres to help us reach our target of 50,000 kilometres. We are going to PROVE that having a stoma is not a barrier to being active!

It sounds a massive target, but the more people that join the quicker we will be able to tell the wider world what ostomates, along with their friends and families, can achieve.

You do not need to be an athlete or have a high level of fitness to take part. Even just taking a regular stroll around the park can improve your health... so why not track the distance you travel and help us towards achieving our 50K target!



Everyone who signs up to take part will receive a free Colostomy UK 50K Challenge t-shirt and a pedometer to keep track of the metres they complete.





Up for the challenge?

- ❖ Register at www.ColostomyUK.org to get hold of your fundraising pack, your free t-shirt and pedometer. If you're not online you can sign up by calling us on 0118 939 1537. If you have any questions please email us at fundraising@ColostomyUK.org
- ❖ If you are part of a club, team or support group see if they would like to sign up as well and get your friends and family to join in too.
- ❖ Encourage people to sponsor you for your part in the 50K Challenge and raise funds to help us make a difference for people with a stoma in the UK.
- ❖ Keep us updated on your progress each week by logging your distances on our website and watch our kilometre tracker get closer to our goal.

Don't forget to send us your photos and stories and share them yourself on social media using the #activeostomates hashtag.



Ahead of getting your pack, here are a few ideas to get you started...

- ❖ Walking the dog.
- ❖ Walking to the shops instead of catching the bus or driving.
- ❖ Mowing the lawn.
- ❖ Take the stairs instead of the lift.
- ❖ Playing a game of tennis once a week.
- ❖ Going for a country hike or climbing a hill.
- ❖ Take part in a 10K run, half or full marathon.
- ❖ Climb Snowdon or Ben Nevis!!



— by Linda

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Update on stoma care products and services

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

New! SenSura® Mio Concave

Ideal for people with curved body profile, hernia or bulge – Concave's star shaped baseplate hugs your body for a snug fit with no creasing. Its elastic adhesive provides a flexible seal and freedom of movement and its central stability ring comfortably supports the stoma for reduced leakage and improved security.

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For samples please call **0115 975 7254** or visit www.independenceproducts.co.uk



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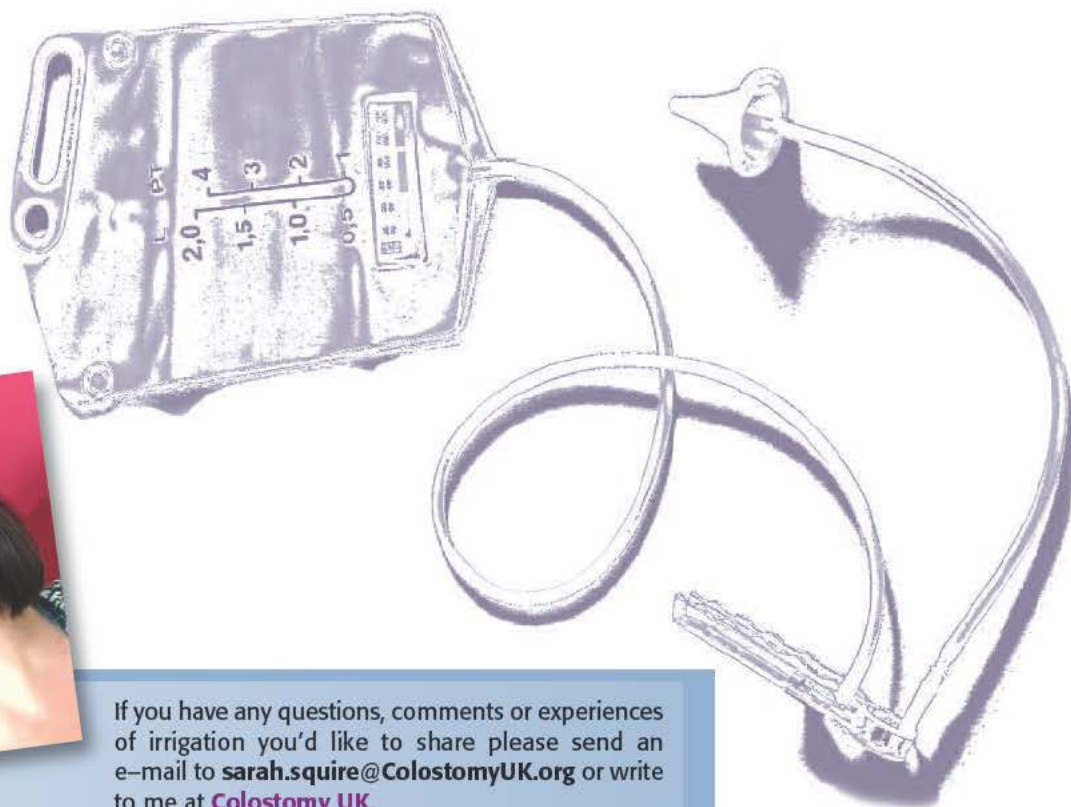
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Further details can be obtained from: Freephone **0800 389 3111**

See our main advert on page 25



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

Sarah Squire

Irrigation and You

We all have colostomies for different reasons. I had mine due to a rectovaginal fistula, so a less common reason than many. This led to incontinence and many embarrassing incidents. Our story today is from June Wilkinson who chose a colostomy over her incontinence so she could return to her active lifestyle.

June writes:

It is around twenty-two years since I had a colostomy formed, and I can honestly say that I have never regretted that decision. The reason it was made is not the usual one – ie malignancy, or other abnormality affecting the colon. My reason was that, at the age of 57, I became incontinent of faeces. This was extremely distressing, and gradually became much worse as the years rolled by. There were many times that I literally had to stop the car, leap out and squat by the roadside, in order to relieve myself. I really did not care who saw this unfortunate event and it happened quite a lot! I have always been an active person, and my husband and I were keen fell walkers. Often, during a walk, this would happen and we then came home with soiled clothing in our rucksacks! I do apologise if this description of the problems I encountered is upsetting to

some readers but I think that it is important to portray the reasons why decisions are made.

I was eventually referred to a gastroenterologist, who diagnosed damage to my anal sphincter, probably due to damage caused by childbirth. I had four children and all had been fairly difficult births. The surgeon suggested an operation to repair the damage, but pointed out that this procedure was “not often successful”. This was indeed the case and, two or three days after the operation, while still in hospital, I knew that it was a failure. After a period of recovery, I saw the surgeon again and he then said that there were only two options left – cope with incontinence or have a colostomy. I agreed to have a colostomy – no hesitation at all. I told him that, as an active person, I could not lead a life with incontinence of faeces and all the distressing implications of this condition!

I was put on the waiting list for the operation and waited many months for it to be done – I eventually found out that they had ‘lost my notes’! In all with tests, consultations and missing notes, it took nearly five years to have a colostomy formed. Despite the delay, I did not change my mind about having the operation. My life was miserable and I was becoming very depressed. I was also having to cope with feelings of guilt towards my husband of only three years, my first husband having died. Was I being fair to him? I need not have worried on that score – he was wonderful, understanding and very supportive throughout.

I returned home and, as my colon had been thoroughly emptied prior to the operation, nothing much happened for nearly a week. My husband and I then went to see Ken Dodd. We had had the

CONTINUED ON PAGE 31, COLUMN 1

CONTINUED FROM PAGE 30, COLUMN 3

tickets for months and I felt well enough to go. Ten minutes after the show started, I felt 'the heavens open' and my pouch was very, very full! I then had to negotiate my way to the nearest toilet, in the dark, and every seat in the theatre was taken! This happened three times during the show. Luckily, I had enough pouches, but it was extremely embarrassing. I think of that nerve-racking experience every time I see Ken on TV!

I was then allocated a stoma nurse who came to see me at home and suggested I try irrigation. This was a new concept and I thought that it sounded wonderful. She then proceeded to show me how to do this and I have now been irrigating for all those years. I found that irrigating gave me back control; I was able to remain active and plan my life accordingly. I have usually irrigated every other day. This works for me, although I have never felt "safe enough" to wear a plug or NO pouch! My husband and I were keen caravanners, and I have irrigated in all sorts of odd places – sometimes having difficulties with obtaining warm water, sometimes problems with finding somewhere to hang the water container and sometimes difficulties with privacy. This was usually when I was using toilet blocks – I could irrigate in the caravan, but space was often very limited, considering all the bits and pieces one needs when irrigating!

However, recently I have been having problems with the pouch filling at inconvenient times, even after irrigating and not related to eating any certain kinds of foods. I have talked to my stoma nurse and my doctor and have had an endoscopy and a colonoscopy both of which showed no abnormalities. They all suggest that it is an "ageing thing", I am 83! Does anyone else have this problem? I also like to use



flushable pouches, but do find that if not changed immediately and the stools are very loose, the pouches tend to disintegrate. Obviously, this is what they are designed to do but it is not always convenient to change the pouch immediately.

At the end of the day, I think that, whoever thought of irrigating to help to cope with a colostomy deserves a medal! Obviously I do realise that not all stomas are suitable for irrigating, but I was one of the lucky ones. ■

Irrigation is a method of colostomy management which involves using specialist equipment to introduce warm water into the bowel via the stoma. The water causes muscular contractions (peristalsis) within the bowel which in turn cause expulsion of its contents.

Many ostomates prefer this method of colostomy management as it gives them a sense of control. If you feel you would like to try irrigation you should first contact your stoma nurse to see if you are a suitable candidate. If you get the go ahead they will then arrange a time to teach you. For more information see the **Colostomy UK** website or purchase the *Irrigation and you* DVD using the form on page 36.

Editor's note: If anyone has any comments for June on her question about irrigation habits changing with age please get in touch with me and I'll pass on any answers.

Please remember these experiences are personal to June. Before acting on suggestions from other ostomates you are advised to check with your stoma care nurse that this course of action is suitable for you.

Win up to £25,000 with Unity

50p
from every £1 goes to
Colostomy UK

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

How it works

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

How to join – three easy steps

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

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

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

If you have any queries please call our hotline on

0370 050 9240

Results & Rules can be checked by visiting

www.unitylottery.co.uk

Or by phoning the Unity winners hotline

0370 055 2291

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

Prizes	£25,000 6 digits	£1,000 5 digits	£25 4 digits	5 Prize Entries 3 digits in the next draw
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1. Your details (please print in block capitals)

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

2. Payment Frequency

How many entries would you like each week?

How often do you want to pay?	<input type="checkbox"/> Monthly £4.34 Direct Debit only	X
(please tick payment frequency and write amount in box)	<input type="checkbox"/> Every 13 wks £13	
	<input type="checkbox"/> Every 26 wks £26	
	<input type="checkbox"/> Every 52 wks £52	
Total Payable		=

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

Signature: _____ Date: _____

Detach the form, put it into a stamped envelope and return to **Unity** at the address shown on the right. They will notify you of your **Unity** lottery number.

Post this form in a stamped envelope to:

The Unity Lottery
Furness Gate
Peter Green Way
Furness Business Park
BARROW-IN-FURNESS
LA14 2PE

For office use only:

3. Select your Payment method

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

☐ Occasionally, Colostomy UK may send you samples and information that may be of interest to you. We do not pass on your details but may use them to keep you informed of what else is available. If you would prefer not to receive these, please tick the box.

T49



Another perspective

by Rita Leaman

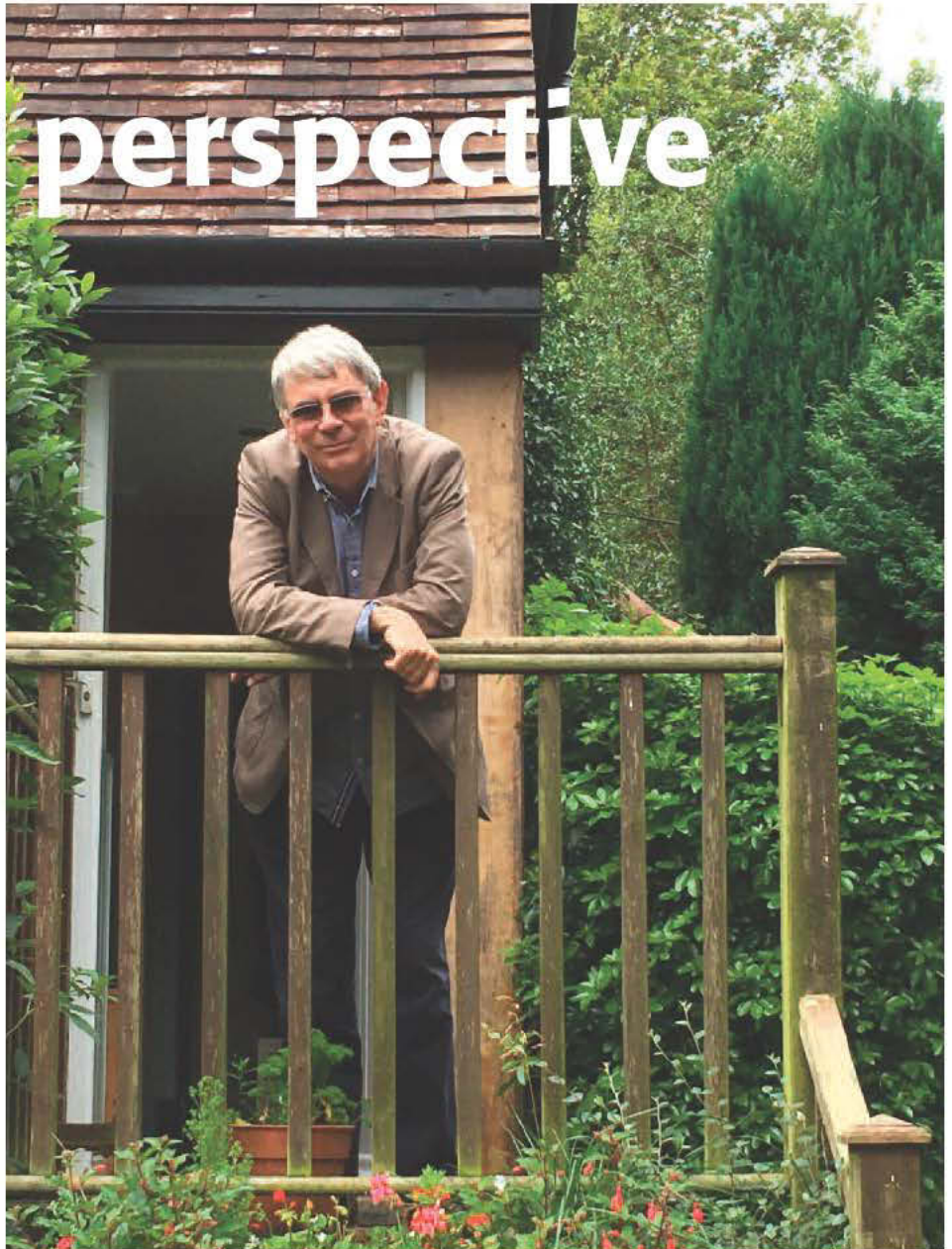
**Sunday, September 30
2013.**

Sunday morning had started much like other Sunday mornings. After breakfast, Adrian went outside to work in the garden.

An hour later, Adrian returned and said that he felt some discomfort in his stomach. This was most unusual, as he was generally a fit and healthy man of 67.

An hour later, he was no worse, but not feeling right and went to bed. His pulse and temperature were in the normal range. Around 2:30pm he asked if there was something he could take for his stomach discomfort. I found some Bisodol. A nurse reprimanded me later. How was I to know? Adrian's temperature was 37.1°, slightly raised, but nothing to get concerned about.

Around 4:30pm Adrian asked for a cup of tea. There was a mucky looking tissue on the bedside table. "What's that?" I asked. Adrian said that he'd felt a little sick and had spat into a tissue. One look filled me with concern. Coffee grounds. "I'm calling 111".



The ambulance arrived and the paramedics were great. They took Adrian's pulse – 144. Why hadn't I taken it again? Adrian was still only complaining of discomfort, no pain. We arrived in Scarborough Hospital A&E at 18:30pm and procedures started. A doctor looked at an X-ray with a colleague. I only heard one sentence: "How old is he?"

At 23:00pm Adrian was admitted to an overnight ward to be seen by the consultant in the morning. The nurse-in-charge took notes from me. Mentioning 'coffee grounds', she said crossly, "Do you mean coffee grounds?". It took some effort to restrain myself. "Yes", I said firmly. I should have kept the tissue.

Returning at 7:30am with supplies, the same nurse-in-charge looked at me in shock. Adrian's bed was empty. For a brief moment I thought the worst, but Adrian's condition had deteriorated and he was being prepared

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for an operation. She expressed surprise that no-one had rung me and suggested they didn't want to wake me up.

I found Adrian dozy and with the consultant, Mr Gatt, who explained that there may be a problem with Adrian's bowel and went through the consent form. He told us the worst result could be a colostomy. Adrian was beyond comprehending, but I knew what that meant. I also knew that a colostomy wasn't the worst possible result. Mr Gatt would ring me afterwards. Outside the Operating Unit doors, I gave Adrian a kiss, knowing I might be saying goodbye. I was left in a long, empty, white corridor. It felt surreal and I recognised that I had gone into mild shock. Why didn't anyone ask me if I was okay? How was I going to get home? Would I like a cup of coffee? Perhaps a chat too? Why hadn't anyone rung me?

I walked home feeling quite peculiar and waited for the phone call. I craved chocolate and started what became over the weeks, a large consumption of Twirl Bars. They became my comfort food. After four long hours the phone rang. Mr Gatt explained that when they opened Adrian up, it was a mess. His bowel had perforated and there was peritonitis. Adrian now had a colostomy, was in ICU and seriously ill. The next 72 hours were crucial. Who should I ring and inform? I couldn't leave it and then possibly have to telephone family and close friends to tell them Adrian had died.

I went back to the hospital and sat with Adrian for a few hours, then went home and opened a bottle of red wine. I needed to fuzzy the edges, but I was still in shock and really wasn't up to talking to anyone and yet there were numerous people to contact. I established a text routine to family, friends and work colleagues that became a lifeline over the next few weeks. Facebook also provided support.

Finding sleep difficult, I rang ICU at 3am, Adrian was stable. I went downstairs and howled. I have cried in despair before, but never have I sounded like that. I felt I



was 'howling to the moon', it was from depths.

The next morning, unable to settle to anything, my mind was all over the place. People were asking if they could come over to be with me. That was kind, but I just wanted to be alone, not having to talk to and cater for someone else. At 11am I could easily have had a glass of wine, but there was the drive to the hospital to think of, so didn't. A bottle of red wine stayed on the kitchen table for two weeks, ready to greet me when I arrived home at 8:15pm each day. Together with the Twirl Bars.

My main concern was that Adrian would not manage. For historical reasons, anything remotely medical was an anathema to him and avoided. How on earth was he going to manage a stoma? This would be his worst nightmare.

Over the next three days, the nursing and care on ICU was wonderful. Mr Gatt told me

that by the time they operated, Adrian's organs were sitting in three litres of faecal matter and he had had to perform a Hartmann's Procedure. To my mind, Adrian's high pain threshold had nearly killed him. Later, Mr Gatt said that he was probably saved by having no pre-existing conditions and he hadn't taken antibiotics for decades.

Adrian remained stable, but I knew that he had little idea about what had happened and wasn't absorbing information. Nurses use medical terms of which non-medical people have no comprehension. "I'm taking your BP (Blood Pressure)" meant nothing to him. Plus Adrian was lacking his hearing aids, so most conversations went right over his head. On day four, Adrian was transferred to a High Dependency Unit. It wasn't until day five when Amanda Rowe, the stoma nurse, explained steadily and clearly what had happened that the enormity began to sink in. When he had



previously heard the word 'stoma', Adrian thought they were saying 'stomach' and with all the dressings, he hadn't properly seen what Mr Gatt had done. Unlike me, he would look away.

Meanwhile, I had to make some serious decisions. On 14 October I was publishing my first book, a book on emotional health. We had arranged publication events in York and London. We had also booked a half-term family mini-break. The book launch was going to be a celebration of the biggest accomplishment of my life. Now I couldn't care less. A box of books arrived on a miserably wet Saturday morning and I cried. It was the biggest anti-climax of my life. At visiting time, I took a book to Adrian. Tears came to his eyes, "I never thought you'd actually do it." He had no idea that, at that moment, it meant nothing to me at all. He was my only concern.

Adrian was getting to grips with changing the bag, but one night, with the medication causing hallucinations, a nurse found him in a distressed state in the bathroom. It was upsetting for him, but the nurse was kind and understanding. The day his bag needed changing seven times in twelve hours indicated a problem and he had to undergo a small procedure to lessen the flow.

Adrian came home on 14 October. He was shocked at how weak he was. We had moved into our house in 2010 after a full renovation. This included installing a wet room downstairs, mainly for muddy/sandy grandchildren. Thank goodness we did. We had moved from a flat with one toilet and living there would have been a challenge. Adrian slept downstairs for two weeks, slowly building up his confidence. Every day we took a few steps outside and walked a little further each time. As a friend had told us from experience, "you have to remember that however far you go, you have to come back too."

Amanda and the stoma nurses were attentive, reassuring and visited regularly, putting Adrian's mind at rest on any query. Adrian responded well to Amanda's direct and honest Yorkshire approach. After two weeks he had the confidence to make it upstairs and in four years, there has only been one small accident.



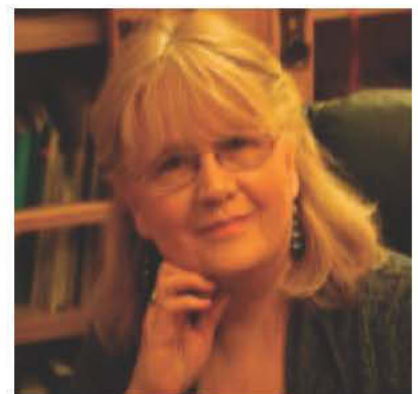
A few weeks later, Adrian looked heavenward and said: "I hope you're proud of me Dad." His father had been a fit, healthy man who, in his late fifties, steadily became a paraplegic and in his sixties became blind. He rarely complained and was still doing household tasks and gardening until his eighties. Adrian's sister had developed Crohn's disease in her early twenties and allowed the disease to define her. A talented woman, she became dependent on benefits and life was a challenge for her and her three children. Adrian had a choice and chose to be like his dad.

Recovery was slow and steady. I decided not to 'mollycoddle' and afterwards, we agreed that it would have been all too easy for Adrian to have become dependent on me. I had been shown how to administer the Warfarin, but he took that on board himself as soon as we got home.

There was a target of February 2014 to aim for. Adrian was due to start a monthly UK lecture tour with a colleague, starting in Manchester and Liverpool, travelling on the train. We decided I would accompany him as a sort of PA, to attend to anything that might arise. My presence wasn't required, but gave Adrian confidence. His frustrations are the ones expressed by others, mainly

the condition of toilet floors with nowhere to put anything and a lack of hooks. He has now become a guerrilla hook sticker, taking adhesive ones in his bag, as well as his 'S' hook.

Adrian still works from home, travelling infrequently, but making great use of the Internet and Skype to work with people worldwide. He made an informed decision not to have a resection with no assurance of a satisfactory outcome and I support his decision. He has kept well, except for one nasty bout of *Campylobacter*. If he feels fed up at all, which is normal, he reminds himself what the alternative would have been. I never ever remotely thought that Adrian would attend a support group of any sort, let alone a stoma support group, but the Scarborough group has been invaluable and Adrian is there most months. Not only does he meet people far worse off than himself, but has met inspiring characters and enjoys an environment where everyone is in the same boat and anything can get talked about. It's a shame more people don't attend.



Tidings, is also an excellent read for us both and Adrian thought that there should be an article giving a different perspective, hence this one. I recycle *Tidings* in a pile of donated magazines in our local café, which is 91m (100yds) from the seashore. I always wonder whether people pick it up thinking it may be seaside related. I needed to give something back to the NHS and now work once a week as a volunteer at the hospital and love it.

I'm writing this on a Sunday. Adrian has eaten breakfast, read some newspapers and gone out to work in the garden.

©RitaLeaman2018

Another way to donate

JustTextGiving – donate by texting

You can now make a donation to the Colostomy UK with a text message!

Whatever mobile network you're on, simply text our unique code **CASS01** and an amount of £4, £5 or £10 to **70070**

Many more supporters are now using their mobile phones to donate.

Donating via text JustTextGiving by Vodafone is **free**. There is no cost to you for sending the text message and your free allowance or bundle will not be affected – the only charge will be the donation itself.

What's more, **100% of your text donation (including Gift Aid) will be sent to the Colostomy UK.**

The amount you donate will be added to your mobile phone bill or deducted from your pay as you go credit. JustTextGiving will send you a link in a text message confirming your donation.

Donations will appear on your JustGiving page – if you have one set up.

**Just text
the code
an amount
to 70070**

**CASS01
£10
70070**

To learn more visit:
www.justgiving.com/en/justtextgiving

Used Stamps needed

Do you have any used stamps you can donate? People are refunded their postage in full as long as they mark the envelope for the "CA" when sent direct to this company (and use commemorative stamps as they become part of the fundraising).

Any stamps are taken but the commemorative stamps are the most valuable because they relate to special events. £10 per kilo is paid including the weight of the envelope.

Instructions to stamp donors:

- No more than 1cm of envelope left around each stamp (as per photo).
- Not trimmed too close so that the perforations are damaged.
- Use special commemorative stamps on the envelope when sending.



Please send your used stamps to:

'CA', c/o Fundraising Stamps Ltd,
59 Mitre Copse, Bishopstoke,
Eastleigh, SO50 8QE

Colostomy Irrigation and You DVD

Order Form Colostomy Irrigation and You (Patients)

Colostomy Irrigation and You is an educational DVD aimed at patients, it has been produced by the **Colostomy UK** to raise awareness about **colostomy Irrigation as a method of bowel management**.

Note: Not all colostomates have the potential to irrigate. It is therefore essential in the first instance to consult your Surgeon/Stoma Care Nurse as they will advise as to your suitability.

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

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



Title: _____

Name: _____

Address: _____

Postcode: _____

Tel: _____

Email: _____

Please allow 30 days for delivery.

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

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

Giving something back

Garry is 44 years old, married to Cherry and they have two sons aged 18 and 20. His stoma was formed four years ago due to diverticulitis. He recently became a volunteer for Colostomy UK.

Garry tells his story:

My symptoms had been going on for a couple of years and I was told that the pain was due to constipation. Then in 2013 my appendix was removed as it was inflamed and strangling the small bowel. Two months later I was told I had diverticular disease. I continued to be doubled up in pain. X-rays, MRI, CT and ultrasound scans didn't identify the cause and in the end the surgeon decided to operate.

When I went for my pre-op appointment I was told it would be a routine operation, carried out by keyhole surgery, and would last about three hours. They said I would have a temporary stoma. At the time I was OK with that, as I wanted to get back to normal.

I went down to theatre on 30 July 2014. The next thing I remember is waking up on the ward and the surgeon telling me that there had been complications. They'd had to open me up because my large bowel had fused to my bladder. The operation had taken over nine hours and at one point they thought I wasn't going to survive. The surgeon had to remove part of my bladder plus more of my large bowel than she intended, and my stoma would be permanent. This took the wind out my sails.

Even though I had been warned that I would come out of theatre with a stoma, when it was actually there I couldn't deal with it. Knowing that it was permanent, I turned to my wife and told her I didn't want to go on.

I was in hospital for eight days after my op. The nursing staff and the stoma nurses at the Queens Hospital, Burton on Trent were absolutely brilliant and very patient. At first, I didn't want to change the bag but they

CONTINUED ON PAGE 39, COLUMN 1





Team Colostomy UK Kit

Buy some kit and show your support for the team! All proceeds go towards supporting out Active ostomates project.

Order online at <http://colostomyuk.bigcartel.com/> or complete the order from below.

Team Colostomy UK Baseball cap

£8.99

Shipping £1.99

100% cotton drill.
Rip-strip size adjuster.

Embroidered
Team Colostomy UK
logo on front and
colostomyuk.org
on back.

One size fits all.

Qty required: _____



Team Colostomy UK Beanie hat

£5.99

Shipping £1.99

100% soft touch acrylic.

Embroidered
Team Colostomy UK
logo on front.

One size fits all.

Qty required: _____



Team Colostomy UK Hooded sweatshirt

£34.99

Shipping £2.99

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

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

Sizes available (Inches):

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

Qty required:

Small _____
Medium _____
Large _____
X Large _____
XX Large _____



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

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

Title: _____

Name: _____

Address: _____

Postcode: _____

Tel: _____

Email: _____



CONTINUED FROM PAGE 37, COLUMN 1

said that I wouldn't be allowed home until I had done it myself.

When I first came home, I had a few problems: my wound became infected, I had to be readmitted to hospital on four occasions, and once had to stay in for a week. I had no problems with the bag itself, but it was a few months before I got my head round having a stoma. A good friend saw that I was in a dark place and his straight talking encouraged me to snap out of it. Then I met one of my mum's friends who has a colostomy and sharing experiences with her finally turned things around for me.

I think, when you first have a stoma it is so important to be able to talk to other people who live with one. I am still in touch with my stoma care nurses and they ask me to talk to their patients. I sometimes see them before their surgery, but I usually visit them in hospital after the operation. After they are discharged I will often keep in touch with them on the phone, by e-mail or visit them at home.

Three months after my surgery, I went back to work as a garage mechanic. When I first came home from hospital I was using a drainable bag but found that quite difficult to handle. Then at an open day I came across the Welland flushable, closed bag. At work I found this so much easier: I had no problem with disposing of a full bag as the liner and contents are just flushed down the toilet. However, I didn't feel the same about my job anymore. It was as if my priorities had changed: I was very aware that I had nearly lost my life and felt I wanted to give something back. When I told my boss that I was leaving, he tried to make me change my mind or at least stay on until

I'd found another job, but I'd made up my mind, and handed in my notice the following day.

Giving up my job in the garage was a good decision. I became a volunteer for Leicester Lowland Search and Rescue. We work alongside Leicester police to help find missing or vulnerable people, especially if they are children or elderly, have dementia or if they have made suicide threats. It was while I was doing this voluntary work that someone suggested that I apply for a job with the ambulance service.

I now work for the NHS in the Staffordshire Ambulance Service. At the moment I am an ambulance care assistant (ACA) and also an advanced blue-light driver working alongside paramedics on emergency transfers to centres which provide specialist care, doing 12-hour shifts from 8am until 8pm. Everyone I work with on the ambulance knows I have a stoma so it isn't a problem if I need to change my bag while we're out on a call. I have, however, had some funny looks when I come out of an accessible toilet wearing my uniform!

So far during my time on the ambulances, I have come across about half a dozen people with stomas. Sometimes I suspect they have one but always wait for them to tell me. When they do, I say I have one too. I always remember a man in his mid-thirties who had a colostomy as a result of a car accident. He didn't believe me and thought I was just saying I too had a stoma to make him feel better. So, to prove it, I showed him. He was quite shocked and said: "And you do what you do. How do you manage that?"



Since I told my work colleagues that I have a colostomy, they have asked what it feels like to live with a stoma. I am quite open with them and take the opportunity to pass on information. I tell ambulance crews to look out for clues that someone might have a stoma: perhaps their patient will keep touching their abdomen to check that their bag is OK. I show them the bag of supplies, ostomates will have with them when they are discharged from hospital, and suggest they take care when fastening the seat belt, so that it is not restricting the stoma or disturbing any abdominal wounds.

I often wish that, when I was younger, I'd chosen a career in healthcare. I have now completed my high dependency training and am hoping I can build on this and progress in the future.

My wife Cherry has been my rock through it all. I have had my share of bad days and still do, but the good far outweigh the bad now.

And finally, my advice to other ostomates: don't be afraid to talk about it – it lessens the load.

Garry Howe

Fundraising Focus

2018 Raffle

Congratulations to Mr Rooney from County Down who won the first prize of £2,500 in our 2017 raffle.

For a list of all the prize winners please email info@ColostomyUK.org

Tickets for our 2018 raffle are enclosed with this issue. If you run out, then further books can be obtained by emailing us or calling **0118 939 1537**.

This year we are offering a first prize of £3,000. A second prize of £500 and four Third prizes of £250.

Tickets can be sent back anytime up until December 14 and the draw will take place on December 21. Winners will be notified as soon as possible after the draw.

Team Colostomy UK Merchandise

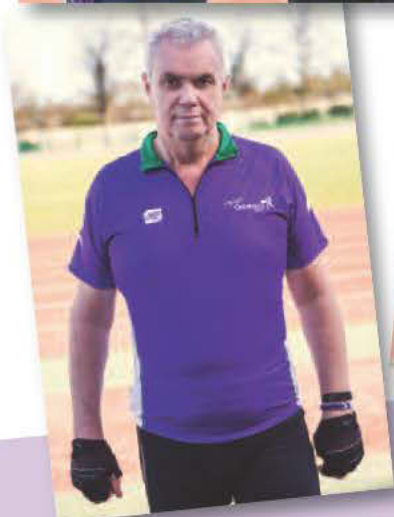
If you've ever fancied taking on a full or half Marathon, cycling challenge, or any other type of event and at the same time raising funds for **Colostomy UK**, then there's never been a better time to do it.

We're proud to be able to launch our new range of 'Team **Colostomy UK**' merchandise. Cycling shirts, running vests and training t-shirts are part of our

exclusive fundraisers kit and are only available to people who take part in events to raise funds for us. If that isn't enough to inspire you, we've included some photos of the new kit to give you that extra nudge.

Anyone can purchase Team **Colostomy UK** Hooded sweatshirts, Beanies, and baseball caps via our online shop at <http://colostomyuk.bigcartel.com/> or see our advert on page 38.

All proceeds go directly to supporting our services, projects, and campaigns.



Lisa and Simon's Saddleback challenges

On May 13 both Simon Rowley and Lisa Tubbs will be cycling 180km (112 miles) to raise funds for **Colostomy UK**, by taking part in the Saddleback Fred Whitton Challenge.

The Saddleback Fred Whitton Challenge is a gruelling 180km (112 miles) sportive challenge ride for charity around the Lake District.

It starts and finishes in Grasmere. The route includes the climbs of Kirkstone, Honister, Newlands, Whinlatter, Hardknott & Wrynose passes.

You can support Lisa and by donating here <https://www.justgiving.com/fundraising/tubnuts>

And Simon by visiting his Just giving page here <https://www.justgiving.com/fundraising/simon-rowley8>



Backing Brian!



On August 4 Brian Hill will be putting his body on the line for **Colostomy UK** when he takes part in the A J Bell London Triathlon. On the day he will firstly be swimming 750 metres, followed by a 20 Kilometre bike ride and finally a 5 Kilometre run. Some of the team from **Colostomy UK** will be at the event which takes place at the Excel Centre, Royal Victoria Docks. It would be great if you could support him too by making a donation on his Just Giving page <https://www.justgiving.com/fundraising/brian-colostomyuk> We'll let you know how Brian does in the next issue of *Tidings*.

Thank you

Unfortunately we don't have the space to thank everyone who has made donations to **Colostomy UK** since the last issue, but we would like to acknowledge a few people and organisations that have been busy raising funds for us:

Adele Louth recently ran the Sheffield Half Marathon for **Colostomy UK**. She took on the challenge for the first time as her Aunt had a stoma and she wanted to do something positive so others could benefit from the same support her Aunt has. Even though Adele has completed her challenge you can still support her by making a donation through her Just Giving page at <https://www.justgiving.com/fundraising/adele-louth>

Shropshire Bums on Tums raised £600 from their open day back in October and donated the funds to Stoma Aid.

Unity Lottery



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

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

Grants and Trusts

We are grateful to the following organisations who have recently supported **Colostomy UK**: The Berkshire Community Foundation, Peoples Postcode Community Trust, The Big Lottery Fund, The CB & HH Taylor 1984 Trust.

Textgiving

You can now make a donation to **Colostomy UK** with a text message!

Whatever mobile network you're on, simply text our unique code **CASS01** and an amount of £4, £5 or £10 to **70070**.

Donating via text is free. There is no cost to you for sending the text message and your free allowance or bundle will not be affected – the only charge will be the donation itself.

What's more, 100% of your text donation (including Gift Aid) will be sent to **Colostomy UK**.

The amount you donate will be added to your mobile phone bill or deducted from your pay as you go credit. JustTextGiving will send you a link in a text message confirming your donation.

Leave a Legacy



WHAT WILL YOUR LEGACY BE?

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

What your gift means

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

Ensure there is always a voice at the other end of the phone.

Train volunteers to provide support at open days and in hospitals.

Fund our campaign for a stoma friendly society.

How to leave a legacy

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

Your solicitor will need the following information on our charity:

Name: **Colostomy UK**

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

Charity Commission registration number: **1113471**

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

Just how important are charity cake sales?

Richard Biddle

What happens when the state takes a backseat in matters of health and welfare? Roll back the clock to Victorian times and you find an answer: voluntary organisations step in and attempt to fill the breach. Often referred to by historians as the ‘age of philanthropy’, the nineteenth century witnessed an extraordinary growth in this sector. It seems that just about every need came to be catered for, from institutions formed by well-intentioned busy bodies for the education of ‘fallen’ women, to ad hoc funds set up by local people for the widows and orphans of shipwrecked sailors. In my home town of Reading, regular church collections were held for the Royal Berkshire Hospital which, like many other hospitals at the time, was a charity.

With such a history, it is perhaps not surprising that the culture of giving has become firmly engrained in the nation’s psyche. Nobody knows how many charities there are in the UK. The figure often banded about is 160,000. According to David Ainsworth, online editor at Civil Society and Media, the number is closer to 400,000. Whatever the true figure, it is beyond debate that many people depend on charities. In turn, charities depend on cash to continue the valuable work that they do. Visit any of their websites and you’ll quickly see how vital it is. A trip down the high street tells the same story with its numerous charity shops and ‘chuggers’, trying to get you to pledge monthly amounts to their cause.

Of course, things have changed considerably in the last century or so. As well as being a prominent provider in its

own right, the state now gives significant financial support to many charities. Television fundraising has been a game changer too, with tens of millions being raised each year by events such as Comic Relief. But, what people perhaps don’t realise, is that money from these sources is not readily accessible to all. **Colostomy UK** receives no such funding and so has to rely heavily on donations and fundraising. Without this, it would be impossible for us to carry on our vital work of supporting people with stomas. There would be no 24-hour free helpline, no independent information literature and factsheets and no *Tidings* to look forward to each quarter. Similarly, we wouldn’t be able to campaign on behalf of ostomates and raise awareness of the issues that they face or run projects to empower them, such as our ongoing work with airports and the civil aviation authority (see pages 11–12 for details).

As readers of *Tidings* will be well aware, stoma surgery is used for lots of different conditions, including cancer, Crohn’s disease and colitis. It is also sometimes necessary following a trauma to the abdomen. Thus, contrary to popular perceptions, all ages are affected – not just people in their senior years. It is estimated that as many as 1 in approximately 700 people in the UK have a stoma. Although the number of urostomies formed each year is unknown, the NHS recently reported

carrying out around 6,400 colostomies and 9,000 ileostomies per annum.

As you can probably guess from the above statistics, thousands of people turn to us each year. So who exactly makes it possible for us to help? Well, as I suggested above, and in common with many other charities, it’s down to two groups. The first is comprised of those kind people that make donations – big and small, they’re always welcome. The second, is our grass roots fundraisers. You can catch a glimpse of what they’ve been up to recently on pages 40–41 (Fundraising focus) As you will see, rather than fitting the popular stereotype, these people are not like Mrs Mangle or Hyacinth Bucket. Instead, they are more like my young friend Charlotte who was recently diagnosed with Ehlers–Danlos syndrome* following years of suffering. On return from her latest stay in hospital, the first thing she did was to organise a charity cake sale to raise money for Ehlers–Danlos Support UK. Like so many of our fundraisers at **Colostomy UK**, she was motivated by the desire to help fellow and future sufferers. This article is dedicated to people like Charlotte, to people like those featured on our Fundraising page and to all those generous people that donate money to us. Rarely, if ever, do they get the recognition and thanks that they deserve.

(An amended version of this article first appeared in Huffington Post 27 September 2017.)

* Ehlers–Danlos syndromes (EDS) are a group of rare inherited conditions that affect connective tissue. Connective tissues provide support in skin, tendons, ligaments, blood vessels, internal organs and bones. For further details visit: <https://www.nhs.uk/conditions/ehlers-danlos-syndromes/>

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

Date of Birth: _____ Month and year of operation: _____

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

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

I would like to make a donation of:

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

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

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

Card number										(Maestro only)			
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Expiry date		Security code		(Maestro only) Start date		(Maestro only) Issue No.							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	D D M M Y Y			

Signed _____ Date _____

giftaid it Thank you for your gift

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

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

Signature: _____ Date: ____/____/2018

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

To the Manager: (Bank or Building Society)

Bank Address: _____ Postcode: _____

Name(s) of Account holder(s):

Account number: _____ Sort code: _____

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

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

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

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

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

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

Name: (IN CAPITALS)

Signature: _____ Date: ____ / ____ / 2018

Registered Charity No: 1113471

 Registered with
**FUNDRAISING
REGULATOR**

Supporting and empowering you



Looking for online support?

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

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

We look forward to welcoming you.

www.ColostomyUK.org

Freephone helpline:

0800 328 4257

24/7



Junior Ostomy Support Helpline

This helpline is available for parents or carers of children with bowel or bladder issues.

Our specially selected team of dedicated parent volunteers provide much needed emotional support when it is required.

Helpline:

0800 328 4257

National Support Organisations

Support organisations for people with stomas and other bowel and bladder diversions

IA The Ileostomy and Internal Pouch Support Group

www.iasupport.org

Telephone 0800 0184 724

e-mail info@iasupport.org

UA Urostomy Association

www.urostomyassociation.org.uk

Telephone 01386 430 140

e-mail

secretary@urostomyassociation.org.uk

Mitrofanoff Support

www.mitrofanoffsupport.org.uk

Telephone 01202 674336

e-mail info@mitrofanoffsupport.org.uk

IOA International Ostomy Association

www.ostomyinternational.org

Junior Ostomy Support Helpline (JOSH)

via the **Colostomy UK** 24-hour free

helpline 0800 328 4257

e-mail info@ColostomyUK.org

Breakaway Foundation

www.breakawayfoundation.org.uk

Telephone 01283 240253

e-mail info@breakawayfoundation.org.uk

Support Organisations for associated medical conditions

Beating Bowel Cancer UK

www.beatingbowelcancer.org

Telephone 020 8973 0000

Bowel Cancer UK

www.bowelcanceruk.org.uk

Telephone 020 7940 1760

e-mail admin@bowelcanceruk.org.uk

Macmillan Cancer Support

www.macmillan.org.uk

Telephone 0808 808 00 00

Monday–Friday, 9am–8pm

Crohn's and Colitis UK

www.crohnsandcolitis.org.uk

Telephone 0300 222 5700

e-mail info@crohnsandcolitis.org.uk

The IBS Network

www.theibsnetwork.org

Telephone 0114 272 3253

e-mail info@theibsnetwork.org

WEBSITE: WWW.COLOSTOMYUK.ORG



Stoma Care Open Days

Attending a stoma care Open Day is an opportunity to find out about all the ostomy products and services available. It is also a chance to meet other people who have a stoma and visit the **Colostomy UK, IA and Urostomy Association** stands.

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

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

CliniMed Event Radstone Hotel (Sapphire Suite)

Larkhall, Lanarkshire ML9 2TZ
18 April 2018 2.30pm
Janet.chesney@clinimed.co.uk

Salts Patient Day

Hilton Garden Inn, Vaux Brewery Way,
Sunderland, Tyne & Wear SR5 1SN
19 April 2018 10–2pm
kim.lemon@salts.co.uk – 07721 556 136

Stoma Care Exhibition Day

The Topn of the Terrace – Norwich City
Football Club, Norwich, NR1 1JE
24 April 2018 10am–12pm
Nicky Pickton/Lucy Russell 01603 286 441

CliniMed Event

Copthorne Hotel, (Crystal Suite),
Aberdeen, Aberdeenshire, AB10 1SU
24 April 2018 10am
Janet.chesney@clinimed.co.uk

CliniMed Event

Tudor Hotel, (Parker Suite),
Airdrie, ML6 0BA
24 April 2018 10:30am
Janet.chesney@clinimed.co.uk

Countess Of Chester Hospital

Stoma care open day
Upton Golf Club, Chester,
Cheshire, CH2 1EE
25 April 2018 1pm–5pm
Danielle Maria or Stacey
Stoma care team

Gloucestershire Hospitals **Open day 2018**

Churchdown Community Centre,
Parton Road, Churchdown,
Gloucestershire, GL3 2JH
27 April 2018 11am–2pm
jollie.smith@nhs.net

Royal Glamorgan Hospital Open Day

Heritage Park Hotel, Coedcae Road,
Pontypridd, CF37 2NP
27 April 2018 1pm–3:30pm
Hannah.Sherrard@wales.nhs.uk

Oxford Stoma Open Day

Tingewick Hall, John Radcliffe Hospital,
Oxford, OX3 9DU
05 May 2018 10am–1pm
Catherine.Brooks@ouh.nhs.uk
01865 (2) 21839

Macmillan Health & Well Being Event

Wirrel University Teaching Hospitals,
Civic Centre, Ellesmere Port, Cheshire,
CH65 0AZ
09 May 2018 12:30pm–4pm
Anne Torkington – DD 0151 552 1860

Medway Stoma Care Open Day

Commissioners House,
Chatham Historic Dockyard, Chatham,
Kent, ME4 4TE
15 May 2018 10am–2pm
Fiona.Anscomb@medway.nhs.uk

MacMillan Wellbeing Day

Blackpool Teaching Hospitals
The Village Hotel, East Park Drive,
Blackpool, Lancs FY3 8LL
24 May 2018 1pm–3pm
Kerrie.Newsham@bfwhospitals.nhs.uk

Scarborough Open Day

Scarborough Rugby Club (Silver Royd),
Scalby, Scarborough, North Yorkshire,
YO13 0NL
02 June 2018 10am–2pm
lisette.backhouse@york.nhs.uk

Nottingham Stoma Open day

The Park Inn Hotel, Mansfield Road,
Nottingham, NG5 2BT
06 June 2018 11am–2pm
Stoma Care Team: 0115 962 7736

Securicare Event

Charnwood Arms Hotel, Coalville
07 June 2018
felicity.nutting@securicaremedical.co.uk

MacMillan Wellbeing Day

Ipswich Hospital, Ipswich, Suffolk
08 June 2018
julie.finbow@ipswichhospital.nhs.uk

Bradford Stoma Support Group

Bradford Royal Infirmary,
MacMillan Centre, Bradford, Yorkshire
09 June 2018 10–12noon

Weston Super Mare Open Day

Winter Gardens, Weston Super Mare
09 June 2018
Lisa Macklin: lisamacklin@nhs.net
or 01934 881338 EX 3738

Ashford & St Peters Hospital Stoma Open Day

Ashford Hospital, Guildford Road,
Chertsey, Surrey KT16 0PZ (details TBC)
14 June 2018
Hilary Lakin, SCN dept sec
01932 722636/723709

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.

Stoma support groups in your county

Channel Islands

Guernsey

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

Jersey

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

England

Bedfordshire

Saturday Social Club
Karen Richards: 0123 479 2278

Berkshire

E.B.O.C (East Berkshire Ostomy Club)
Jackie Dudley: 01344 426 652
Reading Bowel Cancer Support Group
Ted Wingrove 0118 961 8297 or
07974 790 558

Bristol

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

Buckinghamshire

Milton Keynes Stoma Association
Thia Cooper 01908 679 295 /
mksa.chair@gmail.com
You Are Not Alone Stoma Support
Group
Carla 0784 6354 918 e-mail:
carla_wright@sky.com

Cambridgeshire

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

Cheshire

Countess of Chester Hospital Stoma
Support Group
Stoma Nurses 01244 366 170

East Cheshire Stoma Support Group

Catherine McIntosh: 01477 535 071

Stockport Support Group

Marion Caulfield: 0161 320 9400 /
0800 652 6667

Warrington Ostomy Support Group

Jane Shaw: 0192 566 2103

Cleveland

Oops Group

Julie Morrisroe/Carol Younger/Alison
Hall–O'Donnel: 01287 284 113

County Durham

Bishop Auckland Stoma Care Group

01388 814 535 or email:
pgill82171@aol.com

Darlington Support Group

Sister Jacqui Atkinson:
01325 743005

Durham Stoma Support Group

Sister Maxine Santana:
0191 333 2184

Cornwall

Cornwall & Plymouth Bowel Cancer Support Group

The Chairperson: 01726 828 419 or
The Secretary: 01872 241 145,
cbcsginfo@gmail.com or website
www.cornwall-bowel-cancer-support-
group.co.uk

Cornwall Ostomy Support

Ken Jones: 01872 863 106 or
www.cornwallostomysupport.org.uk

Lanhydrock Ostomist Group

Mandy Rowe: 01726 832 642
E: murphy.rowe781@btopenworld.com;
Henry Kendall: 01208 850 986
E: h.kendall380@btinternet.com

Cumbria

Grange Cancer Support Drop in
Marie O'Connor 015395 33279

Stoma Support Groups in North Cumbria

Stoma Care Nurses 01228 814 179

Derbyshire

Diverted Local Stoma Support Group
Diana Manning: 01283 541 311

Devon

Devon IA

Martin Hornby: 01458 251 095 or
email: devon@iasupport.org

Mid Devon Ostomy Support Group

Janice – janice234ford@gmail.com

Plymouth & District Bowel Cancer Support Group

Wendy Wilson or Keith Anderson:
07934 922 156 Facebook: Plymouth
Bowel Cancer

Dorset

Colostomy Urostomy Pouch Ileostomy of Dorset – CUPID (Bournemouth)

Beryl Andrews: 0120 248 3303

Colostomy Urostomy Pouch Ileostomy of Dorset – CUPID (Poole)

Jenny Pipe: 01202 740 440

Colostomy, Urostomy, Pouch & Ileostomy of Dorset – CUPID (West Dorset)

Colin Clare: 01305 853 238

Essex

Connect

Lin Hart 01279 505 273 email:
comeconnectwithus@gmail.com

Mid Essex Stoma Support Group

Paul Foulger: 01245 224 374

N.E.S.S (North Essex Stoma Support)

Brian Waller: 01206 540 449

Redbridge Ostomists Club

Stoma Nurses – Chris/Lisa:
020 8970 8321

STEPS – Stoma Essex Patients Support

01268 451 937 or email:
stepsexsex@gmail.com

Gloucestershire

Vale Stoma Support Group

jfn.dursley@gmail.com or text
07941 827 393

Hampshire

Replummed stoma support group
www.replummed.me

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

Sally: 07527 707069



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

Waterside Stoma Support Group
Hazel Derham: 02380 891 934 or
hayjuder@sky.com

Wessex Urology Support Group
Adrian Kuczynski: 07910 786 978

Herefordshire

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

Hertfordshire

Colonise
Anastasia 01727 760981
Stevenage Ostomistics
Judy Colston: 01438 354 018 /
neilcolston@btinternet.com

Isle of Man

IOM Bowel Cancer Patient and Carer Group
Heather Norman: 07624 480 973
Stoma Support Group
Carole Cringle stoma nurse:
01624 650 212

Isle of Wight

Optimistics
CNS's Sarah Capon & Sarah Varma
01983 534 009
Semi-Colon Club
Tony Crowson on 01983 559 326 or
Cancer Clinical Nurse 01983 534 180

Kent

Ashford Stoma Support Group
Carole Hobbs: 01303 814 014 or
Margaret Webb 01233 628 807
Atoms Support Group
Maria Culleton, SCN: 01227 769 679 or
07827 997 424

Dartford Ostomy Group Support (DOGS)
Tracey, John or Sue: 0794 897 4350 or
dogs-uk@hotmail.com

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

M.O.G.S (Medway Ostomy Group Support)
Helen Or Tracey: 0777 360 5534

Maidstone Stoma Support Group
Judy/Kirsty: 01622 224 305

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

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

SWANS Stoma Support Group
Heather: 07711 445 312

Thanet Stoma Buddies Support Group
Kathy: 01843 291825

Lancashire

North Manchester and Bury Stoma Support Group
Julie Meadows (SCN) 0161 720 2815
or 0784 120 6910

Oldham Stoma Support
June Wilde: 0161 312 5538

Phoenix Bowel Cancer Support Group
Sandra Peet: 01772 683 790,
www.phoenixgroupbvh.com or
email: sandrapeet7@aol.com

Leicestershire

Kirby Ostomy Support Group.
Colostomy, Ileostomy and Urostomy in
Leicestershire
Janet Cooper: 0116 239 2844 /
kosg2013@btinternet.com

Lincolnshire

Friends East Coast Support Group
Betty Williams: 01205 724 120,
Sheila: 01205 364 493
Grantham Support Group
Bobbie/Rachel: 01476 464 822

London

Bowel & other Cancer Support Newham
020 8553 5366 scyana@tiscali.co.uk
Homerton Hospital Bowel & Stoma Support Group
Angela Davy: 020 8510 5318 or
020 8510 7599
Rectangle – Colorectal Cancer Support Group
Regina Raymond 020 7472 6299
South Woodford Support Group
Nurse Christina and Lisa: 020 8535 6563
Surrey & South London Bowel Cancer Support Group
Sue Berry: 01737 553 134 or
John Amos: 0208 668 0796

Merseyside

I.C.U.P.S
Sue: 07742 237 013
St Helens Cancer Support Group
01744 21831, Denys Floyd:
01744 884097 or email: contact@
sthelenscancersupportgroup.org

Middlesex

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

Norfolk

Kings Lynn Ostomy Friendship Support Group
For more info please call
01553 775 698 / 01553 674 962 /
01553 768 271
STARS (Stoma And Reconstructive Surgery social support group)
Sylvia Hughes 01263 733448
sylvia.ruth.hughes@gmail.com
Norfolk Ostomates
Barbara Harris: 01603 417046
07789 581312
Norfolk Ostomates Facebook group

Northamptonshire

Northampton Ostomy Support Group
0780 1316 403 (evenings) or
Trish 07703 188 386

Northumberland

Berwick Ostomy Support Group
Bobbie Minshall: 0771 447 9320

Hexham Ostomy Group
Judith on 0796 792 7286

Northumberland Cancer Support
members@northumberlandcancer
supportgroup.co.uk

Nottinghamshire

North Notts Stoma Support Group
Tore and Nicky Norman:
0177 371 5460
Nottingham QMC Stoma Support Group
Rosemary Brierley: 0115 982 6691
Nottingham Stoma Support
Jenny or Kate: 0115 962 7736/
Mrs B Heath: 0115 966 3073

Shropshire

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

Staffordshire

Outlook
Moiria Hammond 0778 840 2195

Suffolk

East Suffolk Ostomy Group
Marion Fisher: 0147 331 1204
James Pagett Ostomy Support Group (Afternoon Meeting)
Vicki Blackwell on 01493 663363
James Pagett Ostomy Support Group (Evening Meeting)
Sandra Hutchings: 0150 258 5955
L.O.G.S (Lowestoft Ostomy Group Social)
Mandy O'Shea: 07899 913 617
or Bruce Pollard:
brucepollard@me.com
West Suffolk & District Stoma Group
Jessica Pitt stoma nurse:
0163 851 5525

Surrey

Epsom and District Stoma Support Group
Lindsay, Trevor or Sheena:
0137 273 5925
Normandy Colostomy Support Group
Marina Harkins: 01483 233 126
or 07852 554 049 or
Jackie Sanders:
jackie-sanders@hotmail.co.uk or
07815603742. Website:
http://www.normandystomagroup.
wordpress.com
Stoma Support Group
Robin Young: 01428 723 255

Sussex

Brighton & District Support after Stomas (SAS)
Sylvia Bottomley: 0127 355 4407
Chichester Stoma support Group
The Stoma Care Team:
0124 383 1527
The Ostomy Friends Group
Jane Quigley: 0132 341 7400 ext 4552
West Sussex Princess Royal Stoma Support
Tina Walker: 0144 444 1881 ext 8318

Tyne and Wear

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

SUPPORT

NHS Molineaux Centre
John Burchell: 0191 265 1047
Royal Victoria Infirmary Support Group
John Burchell: 0191 265 1047

Warwickshire

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

West Midlands

Coventry Stoma Support
Martin: 0794 738 5643

Wiltshire

Swindon IA
www.swindon-ia.org.uk
Wessex Stoma Support Group
Michael Slater:
wessex.stoma@yahoo.co.uk
or on 0172 274 1233
www.wessex-stoma.co.uk

Worcestershire

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

Yorkshire

Acorn Ostomy Support Group
0758 069 3155 (After 6pm)
Airedale Stoma Support
Sue Hall: 0153 564 6373
Barnsley Bottoms Up Stoma Support Group
Stoma Nurses: 0122 643 2528 or
Celia Utley (Chairman):
0122 628 4262
Behind You (Calderdale & Huddersfield Bowel Cancer Support Group)
Stoma Care Nurses: 0148 435 5062
Dewsbury & District Ostomy
Janet Edmond: 01924 512 041 or
01924 512 072
Hambleton and Richmondshire Ostomy Support Group
Stoma Care Nurses – Judith Smith and Mary Hugil: 01609 764620 /
07736 295131
Harrogate Stoma Support group
Jacquie: 07768 024356
Leeds Bowel Cancer Support Group
Lynda Castle (Colorectal Nurse Specialist): 0113 206 5535
Scarborough Stoma Support Group
Stoma Care Team: 01723 342 388
The Hull and East Riding Colostomy Support Group
Pete Smith: 0798 956 5335 or
Pete Rennard: 0793 951 8642 /
0148 279 3966 or Rosanna Grimsby:
0148 280 1575. www.hercosg.org.uk

Northern Ireland

County Antrim

Colostomy Association Volunteers Northern Ireland
Chris Wright: 0772 071 7771
Mater Hospital
Karen Boyd – Stoma Nurse: 0289 074 1211 Ext 2329
Royal Victoria Hospital – Belfast
Sarah Haughey/Audrey Steele: 0289 024 0503 Ext 3483

County Armagh

Craigavon Area Hospital
Clare Young/Lynn Berry/Janice Garvie:
0283 861 2721
Daisy Hill Hospital Support Group
Bernie Trainor: 0283 083 5000 Ext 2222

County Down

North Down Stoma Support Group
Adrian Ewing on 0785 074 1511
Ulster Hospital
Hazel/Martina: 0289 055 0498

Londonderry

Causeway Support Group
Mary Kane: 0287 034 6264

Republic of Ireland

Dublin

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

County Mayo

Mayo Stoma Support
Marion Martyn: 094 902 1733

Scotland

Ayrshire

Ayrshire & Arran Stoma Support Group
Jim Krasewitz: 0129 222 0945
Stoma Care And Recovery (SCAR)
Maggie: 0129 427 1060/
0781 773 6147 maggie13@sky.com
or Rhona: 0129 455 7478

Fife

Fife Ostomy Support Group
Ishbel Barr: 0159 277 2200

Lanarkshire

Glasgow Stoma Support group
Morag Sinclair: 0141 779 1322 or
Jackie McChesney: 01505 324 052

Moray

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

Scottish Borders

Stoma Support Group
Nancy Fraser: nancyfraser@talktalk.net
or 0145 037 4012. Fiona Gentleman:
r.gentleman@sky.com or 0145 037 1063

West Lothian

GOSH (West Lothian)
Scott Pattison: 07502 163 644

Wales

Bridgend

Bridgend Ostomy Patients Support Group
Anita Brankley (Secretary):
0165 664 5602 or
bridgend.ostomy@gmail.com

Carmarthenshire

W.O.W.S. Wales Ostomy West Support
Judi Hopkins: 01267 237847 or
Julian Boswell: 01554 772877

Conwy

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

Flintshire

Bag For Life Stoma Support Group
In.It.Together
Faye Jones: 0785 275 0772

Gwent

Blaenau Gwent Self Help
Celia McKelvie: 0187 385 2672 After 6pm
Cwmbran Ostomy Support Group (COSG)
Philippa Lewis: 01633 791 339 /
07504 713 069

Mid Glamorgan

C.A.S.S Colorectal and Stoma Support Group
Colorectal Nurse Team on
0168 572 8205

Pembrokeshire

PSA (Pembrokeshire Stoma Association)
Roy Whitfield: 0143 776 0701

Powys

The Bracken Trust Cancer Support Centre
Helen Davies: 01597 823646

Rhondda Cynon Taf

Royal Glamorgan Stoma Care Support Group
Domenica Lear: 0144 344 3053

Swansea

Swansea Ostomy Self Help Group
Glynis Jenkins: 0179 241 8245

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