Summer 2021 | Issue 62

Colostomy UK

AWARD-WINNING

Tidings

Supporting & empowering ostomates

Confidence and the battle to get active again

ED ROWLAND, WITH RICHARD BIDDLE

SHARON MORRIN

Emergency stoma surgery during lockdown

SUE LENNON

Let’s talk about sex

**Real stories
Real people**

Dear readers

Welcome to our new look Tidings which, as ever, is packed with all the features and articles you love!

It's tempting to kick off by talking about the pandemic, but as things in the UK seem to be moving in the right direction as I write this, I'm not going to tempt fate. All I will say though, is that the Colostomy UK team intend to start a gradual return to our offices (indeed it may be underway by the time you read this). Although this comes with the pain of having to travel to work each morning, it's fair to say that everyone (even those who claim otherwise) is glad. It signals the resumption of office banter and that buzz you get working with like-minded and enthusiastic people. Somehow this is never the quite the same online, although it is nice to sneak a peep at the inside of colleague's houses! The return will also mean we will be able to quickly turn around requests for RADAR keys and our literature etc.

There are a number of things I would like to draw your attention to in this edition. I know from calls and emails received that the issue of centralised prescription services is on the minds of some readers. To find out more about this and its likely impact on patients turn to page 7 of Colostomy UK news. In our news pages, you will also find details of a survey we are conducting about the service ostomates receive from companies that manufacture and deliver stoma products. If you have time, then please complete this. You can do it online or via the tear-out survey form on page 8. Lastly, on page 36 you will find a 'teaser' about our upcoming September challenge…

So, what else lies in the pages ahead? In Dear nurse, Mark Johnston talks about pancaking. We also have an important article from Sue Lennon who is a psychosexual therapist. Sex is a topic which, to my mind, isn't given the attention it deserves. As a charity, we are keen to push it to the forefront and get ostomates and healthcare professionals discussing it as a matter of course. We have five Real lives stories. I know from feedback just how helpful these are to people. Anyone struggling to get fit after surgery should find Ed Rowland's experiences useful. John Bigland's and Laura Plant's stories capture that courageous spirit we so often see when people are faced with seemingly endless and insurmountable health issues. Similar is the case with Sharon Morrin who ended up facing the prospect of emergency stoma surgery during lockdown.

Finally, Alan Blacklee reflects very honestly on the price he paid for delaying seeking help. It's a cautionary tale, but one you will be glad to hear has a happy ending!

Best wishes,

Richard Biddle
Editor, Writer & Researcher

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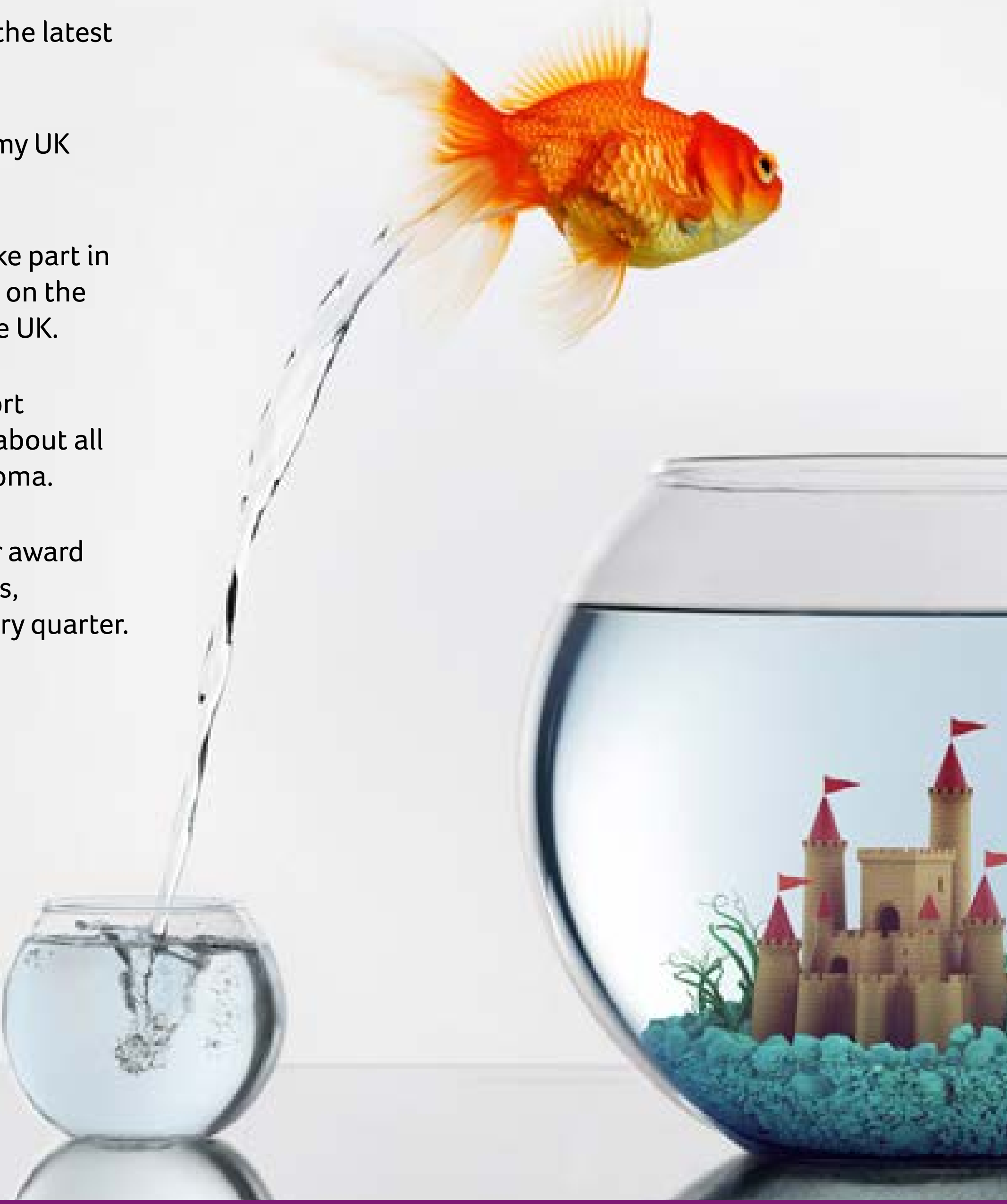

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Get **more** from Colostomy UK by registering with us. It's free, and your friends or family are welcome to join too! Visit www.ColostomyUK.org/join-us/ or call 0118 939 1537.

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

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

How to contact us

Stoma helpline for:

Emotional support, experience-based advice and guidance from a volunteer.
0800 328 4257
24 hours a day and completely free.

Adminline for:

Information packs, ID cards, RADAR keys, travel certificates and Literature.
0118 939 1537
If we're not in, just leave a message.
info@ColostomyUK.org

To request (or cancel) your quarterly copy of Tidings call 0118 939 1537
info@ColostomyUK.org

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

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Donating to Colostomy UK

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

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

news

Libby Herbert
General Manager
Libby.Herbert@ColostomyUK.org

As General Manager of Colostomy UK I am delighted to announce that - after jumping through numerous hoops - our application to work with the charity Pilotlight has been accepted. Pilotlight, whose strapline is 'Great causes deserve great talent', brings businesses and charities together to support strategic planning.

The 'Pilotlighters' are professionals from different sectors, who will be working with us over a 10-month period to help us shape Colostomy UK's strategy and develop our people.

Pilotlight works specifically with small and ambitious organisations like ours, tackling disadvantage in the UK and trying to improve the lives of those most in need. Making no charge for their services, Pilotlight only support around 75 charities at a time, so I am thrilled that Colostomy UK has been selected. Working with such talented people and a fantastic organisation is an amazing opportunity for our charity. Their expertise will help us to evolve which, in turn, will help us to better support ostomates.

Ed Mayo, CEO, Pilotlight said: "At the heart of all great charities is a decision to care. I am delighted to welcome Colostomy UK as a new charity partner for Pilotlight, to support your vital work of care for people with a stoma. Good luck for the work ahead!"

To find out more about Pilotlight visit: **pilotlight.org.uk/**

Welcoming Tom Skilbeck

We are delighted to announce the appointment of Tom Skilbeck who joins Colostomy UK as our Strategy and Change Trustee.

Originally hailing from the north-east of England, Tom now lives in north London with his wife and dog. Tom is a management consultant who helps organisations to deliver people-related change programmes. He has worked extensively in the private sector with clients from all over the world.

As part of his ongoing battle with a complex transphincteric horseshoe fistula, Tom became an ostomate in September 2019 and has a loop-sigmoid colostomy. It was during one of many sleepless nights searching for information that Tom found Colostomy UK and the treasure trove of support and resources we offer.

Tom is thrilled to be joining the board of trustees. He sees it as a fantastic opportunity to use his skills and experience and make a positive difference for ostomates everywhere.

Have your say on the companies that manufacture and deliver stoma products

As part of our commitment to be the voice of ostomates, Colostomy UK is investigating the service provided by companies that manufacture and deliver stoma products.

You can help us by completing a short survey. Your responses will allow us to build a better picture of stoma care in the UK, which we can then use to work with the stoma industry and the NHS.

We want to ensure ostomates get the best support and services possible! To complete the survey, follow this link: **https://www.surveymonkey.co.uk/r/5WMVKCW** or turn to page 8 to complete a paper copy of the survey which you can return by post.

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Centralised prescription services

Traditionally repeat prescriptions for stoma products have been issued by your GP (family doctor). In some areas of England this is starting to change with Clinical Commissioning Groups (CCGs) introducing specialist stoma products ordering services, overseen by stoma nurses.

If you live in Nottinghamshire, South Tees, Rotherham, Luton, and Harrow for example, your prescriptions have been managed by a centralised prescription service for some time. If you're in Halton, Knowsley, Liverpool, St Helens, Warrington, or The Wirral, the new Merseyside & Region Stoma Service will soon take over managing your prescriptions. These services are generally run by an external company.

Although each service operates slightly differently, generally speaking you can expect a monthly call to review your last order and place a new one, along with some health and product-related questions to make sure that your needs are being met. Your prescription is then placed with the dispensing company of your choice or your local pharmacy, who will deliver your order. If your monthly call identifies any health or product issues you will be offered an appointment with a specialist stoma nurse.

Everything points to similar services being introduced in other locations in the future. So why is this happening and how could it affect you?

CCGs are introducing centralised prescription services for four main reasons:

1. To make sure that ostomates get the right products, in the right quantity.
2. To make sure that ostomates have a regular review with a stoma nurse.
3. To improve quality of life.
4. To reduce waste.

Change can be disconcerting, but it is important to remember the following:

- The only real change is that your prescription will now be managed by a prescribing service not your GP.
- The prescribing service will contact you to place your regular order rather than your dispensing company.
- How you receive your order WILL NOT CHANGE.
- Specialist nurses from prescribing services are all trained stoma care nurses. They are there to complement the support you receive from your hospital team, not replace them.

If you have any questions about centralised prescription services please email **info@colostomyuk.org** or speak to your stoma nurse or GP.

Vacancy: Clinical Trustee

Are you a healthcare professional actively working with stoma patients and the stoma community?

We are looking for a registered practitioner to join our board of trustees. You will enhance Colostomy UK's understanding of the challenges clinicians face on a day–to–day basis and help us to forge productive relationships with the healthcare profession. Your input and guidance will shape our services, helping ostomates of today and tomorrow thrive and flourish.

This is a voluntary position suitable for a senior clinician. Charity experience will be beneficial.

To enquire please email: **info@Colostomyuk.org.**

Legacy Update:

Helping ostomates achieve their GOALs

In the last edition of Tidings, we told you about our new eight-week pilot project called 'Giving Ostomates Active Lifestyles (GOAL)'. Everyone taking part in the programme was looking for support with healthy eating and exercise following stoma surgery.

On 15th March, our first six participants logged on to the first online session with Personal Trainer Jo Prance. There was a follow-up session a few days later with Sophie Medlin, Consultant Dietitian.

It is thanks to the legacy of Isabel and Derek Jonas that we were able to run this pilot. We hope the results from it will allow us to do a full roll-out in the future. As many will know, it is common for ostomates to struggle with their weight after surgery and to lack confidence when it comes to exercising.

As a self–funding charity, donations such as legacy gifts are vital. Large or small, they have an extraordinary impact on the people we help and support. As well as funding projects like this, legacies enable us to:

- **Run our 24-hour Stoma Helpline**
- **Provide our volunteers with the training and support they need**
- **Produce Tidings**
- **Fund campaigns**
- **Move closer to our vision of a stoma-friendly society**

To find out more about leaving a gift in your will, see the legacy leaflet enclosed with this Tidings, or visit our website.

For more information about GOAL visit: **colostomyuk.org/active-ostomates/goal-giving-ostomates-active-lifestyles.**

Have your say on the companies that manufacture and deliver stoma products

Colostomy UK

As part of our commitment to be the voice of ostomates, Colostomy UK is investigating the service provided by companies that manufacture and deliver stoma products. You can help us by completing a short survey. Your responses will allow us to build a better picture of stoma care in the UK, which we can then use to work with the stoma industry and the NHS. We want to ensure ostomates get the best support and services possible!
Either complete the survey below and post it to us (Colostomy UK, Enterprise House, 95 London St, Reading RG1 4QA) or follow this link: https://www.surveymonkey.co.uk/r/5WMVKCW

1. Where do you live? ☐ England ☐ Scotland ☐ Northern Ireland ☐ Wales

2. What type of stoma(s) do you have? ☐ Colostomy ☐ Ileostomy ☐ Urostomy ☐ Don't know
Other (please specify)

3. When did you have your stoma formed? Date D D M M Y Y ☐☐☐☐☐☐

4. Have you ever received any communication (call/mail/email) from a stoma product manufacturer or dispenser offering you samples that you haven't requested?

☐ Yes ☐ No

Comment

5. Have you had your stoma products changed without being consulted?

☐ Yes ☐ No

Comment

6. Have you had any products added to your prescription that you felt weren't needed?

☐ Yes ☐ No

Comment

7. Were you actively involved in choosing the stoma care products that you use?

☐ Yes ☐ No

Comment

8. Were you offered a choice of dispenser/delivery company?

☐ Yes ☐ No

Comment

9. Please select all the options that are important to you when choosing your dispensing/delivery company?

☐ Ease of ordering ☐ Complete delivery of order ☐ Quick delivery of order
☐ Provision of free complementary products such as wipes or disposal bags ☐ Telephone advice relating to stoma care
☐ Telephone advice relating to stoma care ☐ Being able to easily sample and trial different products
☐ Annual product review by a Stoma Care Nurse
☐ Please expand:

Comment

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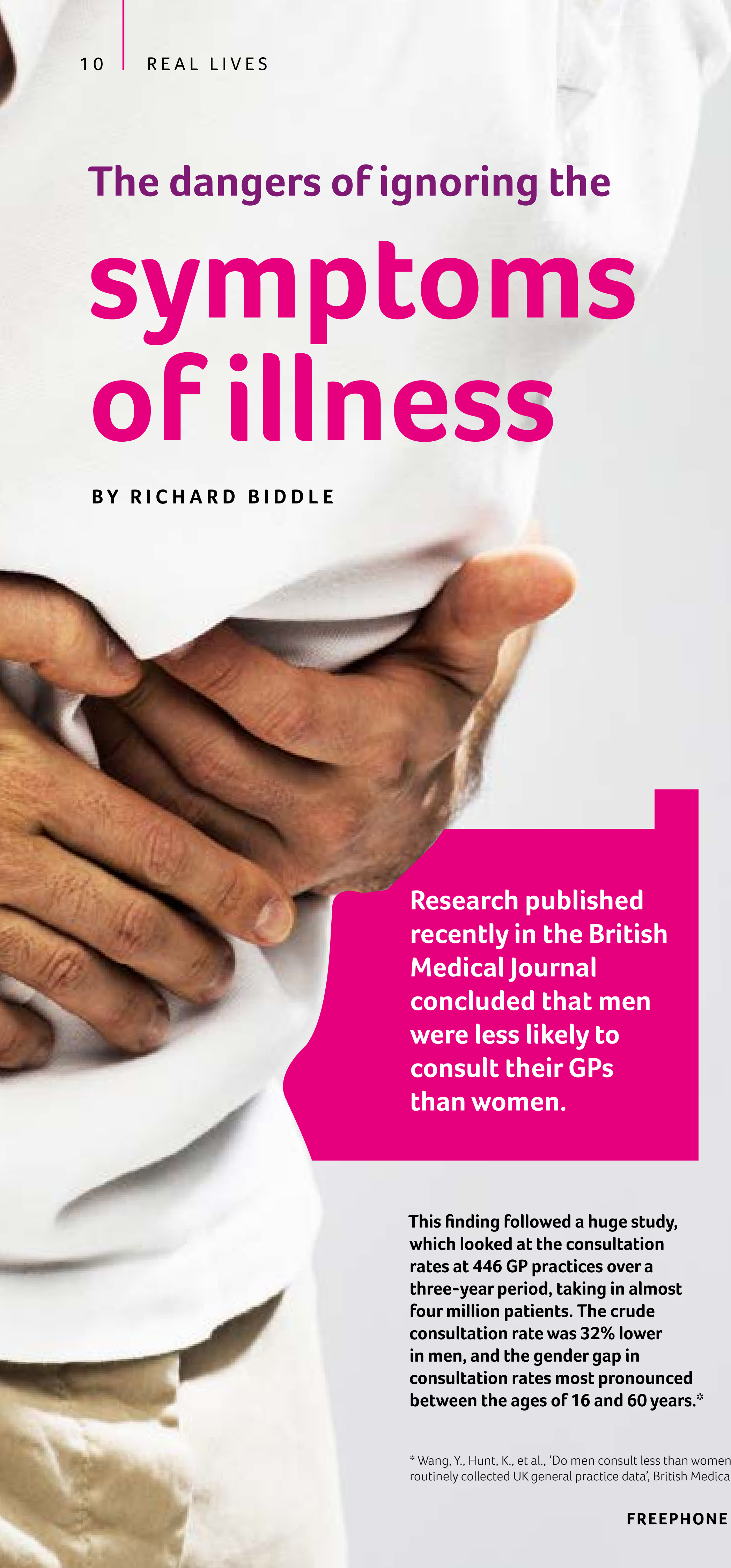

The dangers of ignoring the symptoms of illness

BY RICHARD BIDDLE

Research published recently in the British Medical Journal concluded that men were less likely to consult their GPs than women.

This finding followed a huge study, which looked at the consultation rates at 446 GP practices over a three-year period, taking in almost four million patients. The crude consultation rate was 32% lower in men, and the gender gap in consultation rates most pronounced between the ages of 16 and 60 years.*

Having established with hard evidence something that everyone already suspected (indeed I can almost hear the sighs of our women readers!) the researchers went on to ponder many questions. They queried for example the extent to which the reluctance of men to visit their GP might be a contributing factor to lower male to female life expectancy (particularly as men are more likely to have dangerous occupations than women). They also touched on the implications of delaying seeking help, and how this can lead to patients (both male and female) presenting with a serious disease at a later (and less treatable) stage. The latter is of course very pertinent in the current climate and is something that Colostomy UK's president, Ian Daniels FRCS has warned about recently in this magazine. A similar gender disparity exists with bowel cancer screening, which is all the more worrying given that men are at higher risk of getting bowel cancer than women. According to Public Health Matters, which is the official blog of Public Health England, in 2014 only 53% of men completed their home tests compared to 58% of women.

The purpose of this article is not to examine why all this might be. You will also be relieved to hear that I am not going to inflict on you an analysis of the researcher's detailed findings. But what I do want to do, is to use the experience of one of our readers to show, starkly, what the above can equate to in human terms. My intention, and that of Alan Blacklee, who was kind enough to share his story with me, is twofold: to encourage people to seek help early when they are ill, and, if you are in the age bracket to qualify for bowel screening, urge you to do the tests (and to tell your loved ones to do them too!). This message applies equally to men and women, but I am saying it just a little bit louder to male readers, for obvious reasons.

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* Wang, Y., Hunt, K., et al., 'Do men consult less than women? An analysis of routinely collected UK general practice data', British Medical Journal Open 2013;3.

Alan is now 61 years old and lives in Middleton St. George, near Darlington, with Frances his wife of 38 years. The couple have two grown-up sons and two grandchildren. Alan served 32 years as a firefighter with Cleveland Fire Brigade before retiring from the service in 2010. He then retrained and worked as a Class One HGV driver until March this year, when he "retired for good". Alan is now free to enjoy the things he loves, which include motorcycling, walking, the great outdoors, as well as cooking and photography. I get the impression from speaking to Alan that the motorcycle trumps everything else. As he has been keen to tell me: "Call anytime, I'll always answer, unless I'm out on the bike."

When I asked Alan to tell me his story, he began by referring to himself as "a fool". Taken aback by this (it's not usually someone's opening gambit when I interview them) I asked him to explain what he meant. It quickly became clear:

"I was a typical bloke. I had symptoms for a long time and found every excuse in the world not to attend the doctors, until it was too late."

Alan's first symptoms appeared in 2010, just after he retired from the fire service. These took the form of a strange sensation in the area of his anus and occasional diarrhoea. Alan says these symptoms got significantly worse over time with the appearance of blood when he went to the toilet. Rather than getting things checked out by his doctor, he passed the bleeding off as possible haemorrhoids. Alan lived with this state of affairs for almost four years until one summer day in 2014, when he got the sudden urge to open his bowels. He explains that he was incredibly lucky to get to the toilet in time and then, when he got up from the toilet, was shocked to see the bowl bright red with blood. He says that there was a massive amount of blood.

Looking back Alan still can't believe what he did next… nothing. He rationalised what had happened as a burst haemorrhoid. Alan gets quite passionate when he talks about this incident. He is very clear: "I was an idiot. I knew something was seriously wrong, but instead of doing what I should have done, I accepted my fate. I also hid what was going on from my wife." But, by now, time was running out. Over the course of the next few days Alan started to lose control of his bowels. His hand forced, he finally booked to see his GP. His doctor acted promptly. On hearing how long Alan had been experiencing symptoms she rang the hospital immediately and Alan was booked in for a colonoscopy the day after. Mr Gunning, the consultant who went on to operate on Alan, performed this. He found three abnormal growths in Alan's bowel, which were later confirmed as cancerous.

After a short course of radiotherapy Alan went down for surgery in November 2014. As his cancer had spread circumferentially around the bowel and rectum, it was necessary to remove part of his bowel, along with his anus, sphincter, and coccyx. He also had a permanent colostomy formed. Mr Gunning told Alan afterwards that he was extremely lucky that the cancer had not burst out of the bowel, saying that this was imminent. Alan was in hospital for 11 days before spending a long and painful recovery period, made all the more frustrating due to tailbone pain and stitches which made it difficult for him to sit.

Thankfully, Alan has been cancer free since his surgery and has adapted well to life with a stoma. As you will have picked up, he is 'back on the bike' and when we last spoke, he was counting down the days until he could go out for a pint with his mates. But reaching this point has taken time. Initially he struggled with his body image, and the nerve damage he sustained during surgery will always be there. He has also never managed to regain his fitness, although he sees this as work in progress. Alan readily admits he was lucky, in the sense that he is still alive. Being generally of a positive disposition, he has moved on. He has also learned to live with the consequences of his inaction, although he still wonders what might have been if he had acted on his symptoms back in 2010. This was really driven home to him recently, when an ex-colleague from the fire service was diagnosed early with bowel cancer and had this removed by keyhole surgery and without the need for a stoma. Alan's advice to readers is simple:

"If you take nothing else from my story, take my advice to seek medical help as soon as you have ANY unusual symptoms."

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Emergency stoma surgery during lockdown

BY SHARON MORRIN

When you are only 46 years old, you don't immediately associate a change in your bowel habits with cancer.

Perhaps that's why when I first started to get symptoms, I didn't pursue the matter quite as I should have done. That's the benefit of hindsight for you, and it didn't help me last spring, when things came to a head. I'll never forget the 24 March 2020. As I set off for work that morning the stomach pains started. Putting this down to trapped wind, I persevered, but the pain got steadily worse. On the way back from picking up my son Marty from his Dad's I got some extra strong mints, having heard these were good at getting 'things' going. That evening I ate the whole packet. After a restless night I woke up in agony and my partner Russ called 111, who said to go to A&E.

By the time we arrived, I was doubled over in pain. The doctors thought it was my appendix, but then the questions turned to bowel movements.

I explained they had started to change, from loose to constipated, sometimes with blood showing. In fact, this had been going on for some time. I'd just got used to it. The blood started in 2017 and I got this checked by my GP. It was a bit embarrassing: without the promise of a meal or a night out, he performed a rectal examination. He said it could be internal piles and told me to record if and when blood showed again. For the next three years I saw blood occasionally but put it down to internal piles. It was easier this way. But as I've come to realise, the path of least resistance isn't always the best… The pain side of things came later. The first episode was in December 2018 when me and Russ were at a concert for his 50th birthday. It came on just before the gig started, lasted two hours, and then was gone. Further episodes followed, but I didn't pay them much attention. Why would I? The pain didn't last long.

It was early 2020, when I noticed more changes and saw more blood. I knew I should have gone to the doctors, but like many GP practices, you can only call ours for appointments at 8:00 am. As this is when I leave for work, it's a bit awkward. Sometimes you have to wait 20 minutes to get through, plus I didn't feel comfortable having to say anything to my work colleagues, so I left it. Our lives are ruled by time. Scarcely did I know how little of it I might have had left. If I'm honest, by this point cancer had crossed my mind. I'd recently seen stuff on social media about it. But I didn't have any of the other symptoms, such as losing weight. If anything, I was putting it on. This helped me to rationalise my decision not to call.

Back at A&E, an X-ray showed a shadow in my abdomen. I was admitted for more tests. Coronavirus meant Russ had to go home, leaving me scared and alone. The tests included a CT scan, as they thought it could be inflammation of the bowel or appendicitis. This revealed a mass in my sigmoid colon. The doctors said they couldn't be sure if it was cancerous, but they needed to operate. Two days after being admitted I had an emergency Hartmann's procedure and end colostomy formed. While I waited, I was in contact with Russ and managed to speak to Marty and my mum, but no visitors were allowed. It was very difficult. I didn't even know what a stoma was and didn't have a chance to process what was happening. There wasn't even time to site my stoma.

I came round with people at my bedside. My surgeon delivered the bad news: the mass was cancerous, and a lesion had been found on my liver.

This came as a huge shock. I had lost my dad 16 months earlier to oesophageal cancer. My goal now was to recover from this operation and get used to living life with a stoma. I found everything overwhelming at first. After five nights in hospital, I went home. Recovery was hard. It was three weeks before I could straighten up and sleeping was difficult. Russ was a huge support, helping me shower, changing my stoma bags, etc. It wasn't plain sailing; there were a few accidents, and I don't think the sofa will ever be the same again. But we just laughed it off; it was all part of getting used to this new way of life.

On the 14 April 2020, I was well enough to celebrate my 47th birthday. Stuck in lockdown it was a quiet day spent with Russ and Marty. That evening the Indian takeaway we had, washed down with a couple of glasses of wine, prepared me for my follow-up appointment at the hospital. It was here my diagnosis was confirmed and the consultant told me I was lucky to be alive, as apparently the tumour was about to burst. Hearing this gave me goosebumps. Arrangements were made for me to have a colonoscopy through the stoma to check my bowel was ok and an MRI scan on my liver. The thought of the former freaked me out. My stress levels on the day weren't helped by all the waiting between patients due to the heightened care being taken with Covid-19. The procedure wasn't as bad as I expected. The worst part was the Moviprep I had to take the night before, leading to regular toilet trips to empty my bag!

The MRI scan confirmed four lesions across the liver, one of which was close to where the blood vessels enter and another that was too big for surgery. This meant four rounds of chemotherapy in late May. I found this difficult to cope with. It played havoc with my calves and I suffered painful constipation which lasted up to four days each time. Stool finally passing through the stoma was like having contractions, but I felt such relief afterwards. Post-chemo CT and MRI scans showed the tumours had shrunk enough for surgery. I was given notification of my pre-surgery appointment on the same day as I received news that Marty's father had

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died unexpectedly. My emotions were all over the place, having to tell my son the awful news while trying to prepare for major surgery. I was more nervous this time round as I had the time to think about things. Fears of not coming out of surgery swept over me. I was scared about leaving my child an orphan. In the end, they removed 60% of my liver, along with my gallbladder. Originally it was meant to be 40%, but chemo can change the way the liver looks, so it was decided to remove everything that looked suspicious. I stayed in for seven days, again with no visitors.

Shortly before Christmas I had follow-up bloods and another CT scan. In January 2021 my oncologist informed me all the cancer markers were low, and my lungs, liver and bowel were clear, but due to an enlarged para-aortic lymph node in my aorta, I had to have a PET CT scan. This showed small, highlighted lymph nodes in my neck and rectum. I am now due to have a fine needle aspiration of the neck (biopsy). It has been an emotional 12 months, compounded by coronavirus visiting restrictions in hospitals, which left me scared and alone at some of my darkest moments. I've shed many tears from the frustration of going through this; from clothes not fitting anymore because of my stoma to not being able to be with the people I love. But I have remained positive. Russ has been my rock, as well as my carer, nurse and housemaid! Thanks to him I have kept going. He has cheekily named my stoma "Kuato" from the film Total Recall and bestowed on me the DJ name "Atoms" a stoma anagram, for when we can start DJing again. The professionalism of NHS staff and the support of friends, family and work colleagues has been vital too, as has the help I have received from Colostomy UK and Bowel Cancer UK.

I hope my story will help others who are going through a similar journey. I hope, too, that my experience is a salutary reminder to everyone not to delay acting on the symptoms of illness. As I have learned, you are never too young to get cancer.

Annual Prize Draw

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Colostomy UK volunteers

Emma Howell
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Volunteer @ColostomyUK.org

I know from speaking to our volunteers just what a worry tackling the 'firsts' can be after having stoma surgery – be that the first meal out, the first time going to the shops, or the first time using a public toilet. For many new ostomates these opportunities have been delayed by lockdown or shielding over the last year, and therefore their worries have amplified. With this in mind I asked the team what advice and tips they would give new ostomates. Hopefully, even our more stoma-experienced readers will pick up a nugget or two from what follows…

The overarching message from our volunteers was 'be prepared and remember no one will know that you have a stoma – unless you tell them'. Many of our volunteers have their own pre-packed travel or emergency bags, which they take with them whenever they go out, whether it be to the shops, the cinema or even round a friend's house. The one pictured opposite is used by Helpline volunteer Sue. It contains from the top, clockwise: non-descriptive bag to carry everything, stoma bags, safety item (a folded puppy training pad for extra protection against leaks), dry wipes, bottled water, adhesive remover (spray or packet), hand sanitizer, over-the-counter output thickeners*, air freshener and black disposable bags.

Sue said: *"I always have Puppy Training pads (Amazon £13 for 50), smaller, neater and thinner than hospital bed pads. I fold these up and tuck them between my pants and ensure it covers my stoma bag, so that if the bag leaks, it goes onto the pad, rather than my clothes. I promise you, this tip has helped a lot of ostomates feel safe and more confident."*

Other volunteers, such as Chris, also include a peg in their bags, which they find useful for holding upper clothes out of the way when they are changing their bag. Donna also takes a roll of microporous tape. In her experience it can repair, temporarily, most problems!

As well as a travel/emergency bag, many of our volunteers also take their ID card and RADAR key. Finding accessible toilets is a topic that most of our team mentioned. You can use 'Toilet Map', 'AccessAble's Accessibility Guide', or 'Changing Places Toilets Searchable map' to find toilets near you. Bernard said: *"don't be afraid to use the accessible toilets and if you get funny looks from people just out-stare them or ask them if there's a problem – in my experience it usually works very swiftly! People need to remember that not all disabilities are visible."*

Recycle and Raise Funds

We've teamed up with 'iCollectClothes' to offer a hassle-free way of donating items you no longer want.

They will collect clothing, shoes, linen, bedding, towels, curtains, accessories (bags, belts, hats, scarves), books, DVDs, CDs, soft toys, electronics and small domestic appliances and convert them into a donation for Colostomy UK.

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

If you live in Greater London, the West Midlands or Merseyside you can book a collection. For all other areas give them a call and they will be able to advise when they will be collecting near you.

Book your collection by calling **0344 879 4417** or book online at **icollectclothes.co.uk/donate/colostomy-uk**

iCollectClothes

Here are some other tips/ advice from the team:

- **Make sure your bag is secure and empty before you go out.**
- **When you first venture out, have a purpose, like getting a newspaper and chose a time when you think your stoma is less likely to be active.**
- **Don't feel pressured (either by yourself or others) to make that first trip out. Take it when you feel ready.**
- **Don't be afraid to use accessible toilets.**
- **Go for a short walk to start with. Then as your confidence grows, get more adventurous!**
- **If possible, go out with a family member or friend, so you feel supported.**
- **Stay local at first so that you know the area and where toilets are in case of need.**
- **If eating out, avoid anything too rich or spicy.**
- **Try to remember that no-one knows you have a stoma. Try to be confident!**

And finally, as a number of our volunteers said:

- **Think positive. You can do this! If in doubt, phone the Stoma Helpline (0800 328 4257) and speak to a volunteer who has been there, done it and got the stoma bag!!**

Take care, Emma

* Before trying output thickeners, speak to your stoma care nurse, as excessive use can cause blockages.

✓

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Back to content page

Confidence and the battle to get active again

ED ROWLAND WITH
RICHARD BIDDLE

If you've followed the exploits of our Rugby League team, then you will know that its impact has extended far beyond the pitch.

Media coverage of fixtures has brought stomas and the needs of ostomates to a wider audience and, at the same time, raised awareness of Colostomy UK and the work our charity does in supporting and empowering ostomates.

But it's also about the difference it makes at an individual level. It's about the effect it has on somebody when they don the purple kit, tie their boot laces, and make their first tackle. It's about people like Ed Rowland.

Ed, who is 38 and a police custody sergeant, is married to Kate who is also a police officer. The couple have two children, Maggie who is now five and Grace who is one. Ed had stoma surgery in October 2016 after a ten-year battle with ulcerative colitis (UC). He was diagnosed following a foreign vacation, when he came back with what he thought was a post-holiday 'tummy'. However, rather than improving, it got worse. At the time he was a frontline police officer. For a man in his early twenties, this was his first encounter with serious illness. His weight dropped dramatically, and he became increasingly concerned about what was going on. In the end, Ed was admitted to hospital and diagnosed. Over the next decade, he found himself in and out of hospital with flare-ups. He was also on and off steroids, while all the time battling to stay well enough to continue doing the work he loved. Ed says that the stoma option was broached with him, but he always shut these conversations down quickly. As he said: 'I wasn't prepared to even consider it'.

Ed's views changed when UC nearly caused him to miss the birth of Maggie. This was the moment when he realised that he couldn't continue as he was. During his next flare-up Ed was told he was out of options and so the next day had surgery. Post-op he was determined to get his fitness back. Ed talks in terms of his stoma giving him a new lease of life. He began to put on weight and, as he puts it: 'feel normal again'. For the first time in many years Ed was able to do what he wanted without the fear and anxiety that UC had cursed him with. That's not to say of course, that he didn't have to adjust to life with a stoma and all that brings.

Ed's road to fitness started with the gym. He took things gradually, welcoming the fact that for the first time in years, he didn't need to keep dashing off to the toilet. He then progressed from the gym to running. All the while his confidence was slowly returning. This brings us to early 2019 when Ed read about the Colostomy UK Rugby League team and decided he was ready for such an opportunity. Ed made his debut that summer against the Political Animals. This is what he said about the experience:

"I was nervous about leaving home and traveling to Leeds. I had recently moved to the north east with my family and transferred jobs. This was a massive change in my life, and now I had volunteered to pull on the Team Colostomy UK rugby league shirt! I had never played league before, and grew up going to a union school… but that was 20 odd years ago, and since then I had grown older, bigger, with more life experience, and there was the matter of having a stoma…

I was confident in taking hits and rolling around on the floor from work but saw rugby as a real test. I purchased a pair of cheap boots, packed a bag of kit, made sure I had the armour I wear for work, and set off first thing. I had no idea where I was going, so was completely reliant on the sat nav. After a few wrong turns, (which with UC would have set off a need for the toilet) I arrived at the ground and was met by a smiley Giovanni and Libby who introduced me to team members as they arrived.

I then went to the changing room. It was the first time I'd actually got 'changed' in front a group of people with my bag. I had been on holiday and let it all hang out, but this seemed different. I had a sneaky look at the variety of support wear, bands and protection plates on show. I was wearing my work ostomy guard but debated whether to wear it. I decided I would as it would give me a bit more confidence in taking a hit. It then dawned on me…I wouldn't be able to wear my glasses. I wear them all the time and things are blurry without them. I took them off and made my way out squinting and worrying that I would find it difficult to see the ball, let alone catch it when it was passed to me!

Take your time. Small progressions make a massive difference in the long term. Start light and build yourself up steadily.

Just then I was spun a ball from a blurry faced player in purple. I caught it and my eyes adjusted a little. We then proceeded to warm up with a few up-and-under kicks. The first of these, I nailed a catch, pulling the ball into my torso and dropping down to my knee. My confidence rocketed and I was suddenly that 15-year-old schoolboy back on the rugby pitch. I was told I would be playing as second row. I was comfortable with this as I had played hooker at school, and being a forward, I wouldn't need to worry much about lines and formations, or so I thought. I soon realised rugby league is very different to union. The whistle blew to start. The first time I received the ball, I thought I could still move like a teenager, and tried a side step past an opposing player, which I did, only to realise the ball had been snatched out of my hands. But the whistle blew. I received the ball again, and took it into the tackle, holding it tight this time. I took the hit and went to the ground with the ball nestled into my right armpit.

As I hit the ground, I felt a crack and a pop as the wind was knocked out of me. It was lucky I couldn't talk as there were a bunch of expletives in my head as I stood up. I heard my teammates yelling, but I couldn't breathe let alone 'play the ball'. I saw the ball on the ground and used my foot to roll it behind me as I had seen on TV. I then bent over with my hands on my knees to catch my breath while the game continued.

I felt the adrenaline rushing and the pain subsiding. I was hooked. I loved being part of this team, despite feeling I wasn't any good! But it didn't matter. I took the ball into another tackle to be held up by two players who gave me a pat on the back, one of whom said 'good lad', in a distinctive northern accent. I made a good couple of tackles, took a few good hits, passed the odd decent ball, missed a couple of tackles, and loved every second of it.

Afterwards, it was great to share a pint with both teams, talk about the game, and watch the rugby on the bar TV. I left for home with a boost of confidence, a new network of friends and, of course, a few battle scars to be proud of!"

Regaining your fitness after stoma surgery can be a real challenge. And, of course, fitness means different things to different people. Not everyone aspires to playing a contact sport like rugby. For some it's about getting out and walking or doing the garden. However, Ed's advice on the matter applies to all: "Take your time. Small progressions make a massive difference in the long term. Start light and build yourself up steadily. Wear hernia support. Enjoy the progression and with it the boost to confidence that follows. Above all, as difficult as it may be, try and see your bag as a trophy of a previous illness or battle, not a representation of defeat."

Colostomy UK

fundraising

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

Supporting Colostomy UK

We are a self-funding charity and rely on donations and grants to fund all our activities. Every £1 that you donate really helps.

There are loads of ways you can support us. Please visit **https://www.colostomyuk.org/get-involved/fundraising/** for more details.

Despite the challenges we've all faced over the last twelve months we're both proud and humbled that people have continued to find ways to support us. Unfortunately, we don't have the space to acknowledge everyone, but are delighted to feature some of our fundraising heroes in this issue.

Carmen can

The fabulous **Carmen Carmichael** is taking on the virtual Land's End to John O'Groats challenge - completing 874 miles this year – to support Colostomy UK, and if that's not enough she's also fundraising through charity auctions and has raised £660 already! We wish Carmen the best of luck with her awesome challenge!

Karen's 10k

Despite the Weymouth 10K being cancelled **Karen McGuinness** still managed to don her Team Colostomy UK running vest and complete 10,000 kilometres on her own. She also raised a brilliant £200 as well. Thank you, Karen.

Make a difference with Amazon Smile and Facebook

Do you shop on Amazon? You can raise free donations for Colostomy UK when you shop with AmazonSmile! Every £1 raised helps us to better support ostomates.

AmazonSmile customers can support Colostomy UK in the Amazon shopping app. Just open the app, go to the main menu and tap 'Settings'. Choose 'AmazonSmile' and follow the on-screen instructions. Thank you and happy shopping!

Another easy and straightforward way to support is by setting up a Facebook fundraiser on your birthday. You can encourage your friends, family and followers to donate too. For more details visit **facebook.com/fund/colostomyuk**

100 miles in May

for Colostomy UK

A team from Pentagon Corporate Fleet spent May challenging themselves to cycle, walk or run 100 miles over the course of the month to raise money for Colostomy UK!

We're really grateful to Hannah, Sarah, Chad, Nat, Freya, Janine, Jon, Anne, Debbie, Ian, Richard, and Tamara for choosing to both raise funds and awareness for our charity.

Hannah explains why they chose to support us. *"Colostomy UK is a charity very close to my heart as both my mother and grandfather have stomas.*

In February 2020 my mother, Jeanette, was invited for routine screening, initially a sigmoidoscopy and then a colonoscopy. A high number of polyps were found (not all could be removed) and she was then referred for genetic counselling and subsequent testing. After three long months of waiting, she was informed that she carries the AFAP gene, thus increasing her risk of bowel cancer. She took the difficult decision to have an irreversible ileostomy which was carried out on the 8th February this year. We believe this is genetic, as 15 years ago my grandfather, Terry, (her father) had bowel cancer, also resulting in an irreversible ileostomy. It is possible I will also require the support of the charity in the future as there is a 50/50 chance I also carry the gene... my journey to find that out has just started!

Both my mother and grandfather are doing well. I am so proud of them, but I really believe that this is a subject that needs to be spoken about more. People have to be more comfortable talking about it. The work that Colostomy UK does in supporting ostomates and their families is so important."

Freya's father is likely to need a colostomy too, due to Crohn's Disease. At the moment it affects his day-to-day life and limits things they can do as a family. Freya mentioned they no longer go on family bike rides or camping and have to plan meticulously when they do go out anywhere.

"It truly is a hidden part of life which needs to be 'out there' more, and I hope by doing this May challenge we can make an impact!"

You can still support the team and Colostomy UK by donating through their Just Giving page: **https://www.justgiving.com/fundraising/colostomyuk100miles**

Picture perfect

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

Her artwork of male and female forms with either a colostomy or ileostomy are now available for sale via our online shop, and Emily is kindly donating all the proceeds to Colostomy UK. You can order online at: **https://colostomyuk.bigcartel.com/**

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

Back to content page

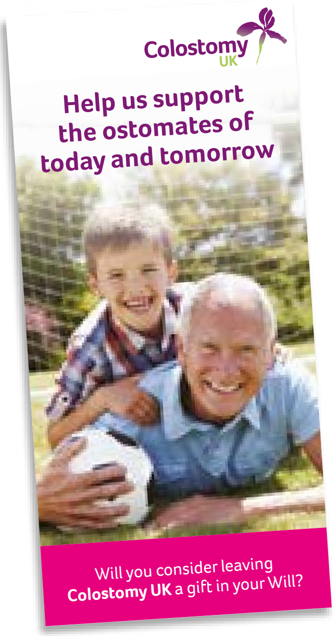
In the bag!

If you're planning a clear-out, you can donate your unwanted clothes, paired shoes, linen, bedding, towels and curtains to ICollectClothes, and at the same time generate much needed funds for Colostomy UK!

They can also collect accessories (bags, belts, hats, scarves), books, DVDs, CDs, soft toys, electronics and small domestic appliances.

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

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



Colostomy UK

Help us support the ostomates of today and tomorrow

Will you consider leaving **Colostomy UK** a gift in your Will?

Legacy

Your copy of Tidings includes a copy of our legacy booklet. If once you have taken care of your friends and family, you would like to leave a gift in your will to Colostomy UK, we would be delighted to receive your support.

For more details please see the booklet or email us at **info@colostomyuk.org**

Something fishy?

A huge thank you to Martin and Lee from Yateley West Fishery fishing club who have chosen Colostomy UK as the beneficiary of their annual charity weekend this August.

They're hoping to raise as much as possible through a combination of donations, tournament entry fees, and a raffle over the weekend of 6th to 8th of August. If you'd like to support their big weekend, you can also visit their Just Giving page at **https://www.justgiving.com/fundraising/martin-gardener2** with donations going to Colostomy UK.

YATELEY WEST FISHERY

Stamps to be cut/torn from recent mail.

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

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

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

Colostomy UK

No one should face stoma surgery alone.

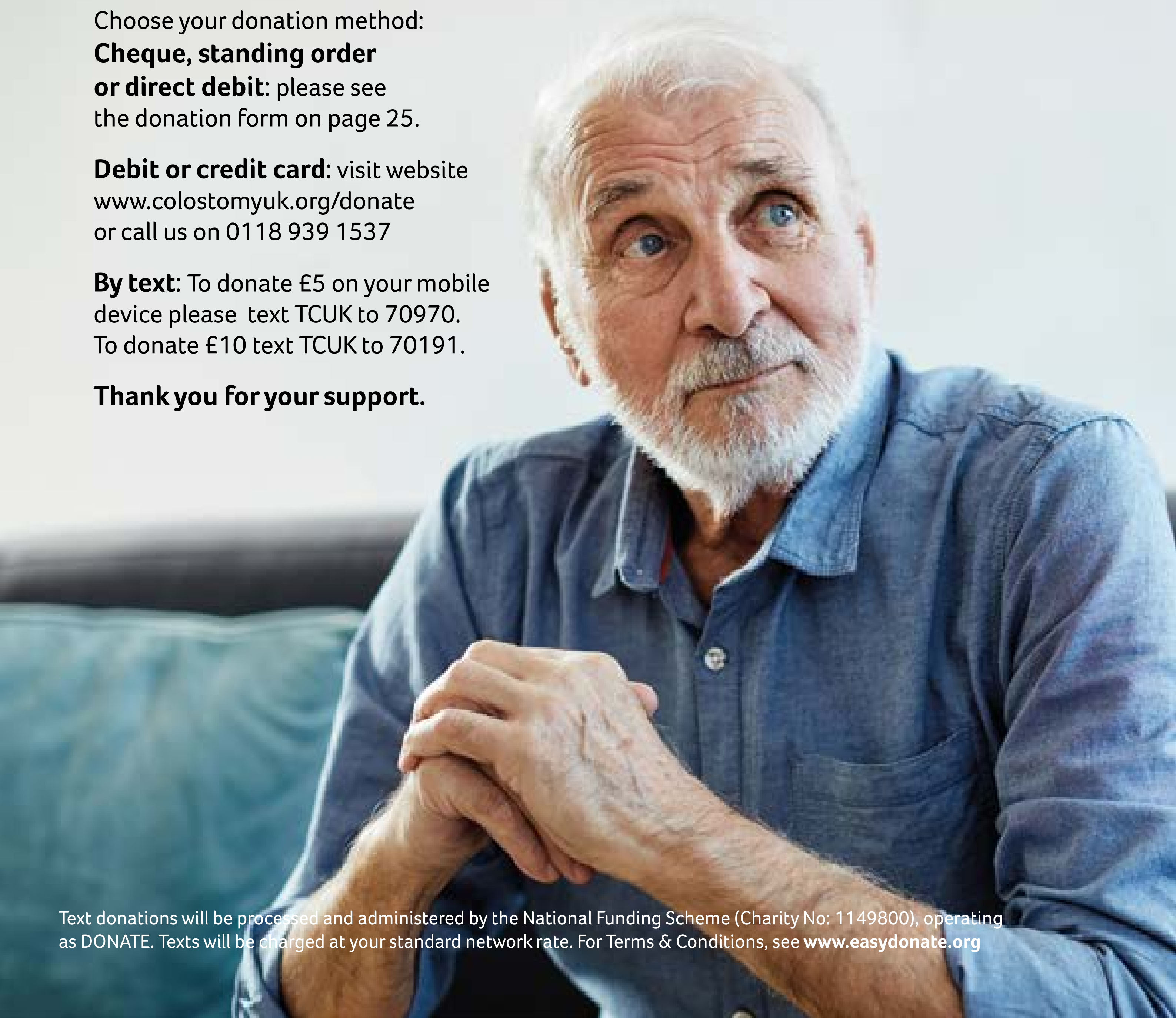
Help us to make sure they don't. Donate now.

Choose your donation method:
Cheque, standing order or direct debit: please see the donation form on page 25.

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

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

Thank you for your support.



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

Colostomy UK

As if by **magic**....
Make your donations worth
25% more
at no extra cost to you!

If you're a UK tax payer, tick the Gift Aid box on the donation form (see page 25) so that we can claim an extra 25% from HMRC at no cost to you. Gift aiding your donation provides us with more funds to focus on the things that matter to you, such as providing support through our stoma helpline, campaigning for stoma-friendly toilets producing this magazine, or getting more ostomates up and active. For more information email fundraising@colostomyuk.org

☑ giftaid

Please support Colostomy UK

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

Colostomy UK

Please complete in BLOCK CAPITALS

My Details: Title*: First name*: Last name*:
Address*:
Postcode*: Phone Number:
Email*: Gender: ☐ Male ☐ Female ☐ Other, please specify:
Date of birth: Date of surgery:

If you are new to **Colostomy UK,** how did you hear about us?

Are you: ☐ An ostomate ☐ A carer ☐ A healthcare professional ☐ Family or friend
☐ Other, please specify: Stoma type: ☐ Colostomy ☐ Ileostomy ☐ Urostomy

Reason for surgery:

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

You are in control of the information you receive and can change your options or unsubscribe at any time. I would like to be kept informed and receive (please select and tick the box):

- ☐ Tidings the quarterly **Colostomy UK** support magazine
- ☐ Monthly **Colostomy UK** support e–newsletters
- ☐ Post from carefully selected third parties (eg about open days or offers)
- ☐ Emails from carefully selected third parties (eg about open days or offers)

Any other details you would like to share with us

Data Protection: Colostomy UK is registered under the general data protection regulation (EU) 2016/679. The data we hold is managed in strict accordance with the Act. We do not disclose any information supplied by you to any third party organisations. (However, we may send you their promotional information, which we think may be beneficial.)

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 ☐ £25 ☐ £30 ☐ £50 or other amount (please state) £
☐ monthly ☐ quarterly ☐ annually starting on the ☐ 1st ☐ 15th ☐ 25th of the 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)
Signed: Date: / / 2021

ONE-OFF DONATION

☐ £25 ☐ £30 ☐ £50 or other amount (please state) £
☐ I enclose a cheque or postal order made payable to **Colostomy UK**
☐ Please debit my Visa/Mastercard/Maestro Card with the amount specified

Card number (Maestro only)
☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐

Expiry date ☐☐/☐☐ Security code ☐☐☐ (Maestro only) Start date ☐☐/☐☐ (Maestro only) Issue No. ☐☐

Signed Date D D M M Y Y

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.

Signed: Date: / / 2021

T62

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

Registered Charity No: 1113471

Registered with FUNDRAISING REGULATOR

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

Fullx3 07v01r00 CUK Donation form - Press | Date of Publication: March 2021 | Copyright ©2021 Colostomy UK | Registered charity no. 1113471

Charity Name: Colostomy UK

Instruction to your Bank or Building Society to pay by Direct Debit

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)

Bank/Building Society account number

Branch Sort Code

Service User Number

6	9	1	2	1	3

CAF, Kings Hill, West Malling, Kent, ME19 4TA

Instruction to your Bank or Building Society
Please pay Charities Aid Foundation Direct Debits 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 Charities Aid Foundation and, if so, details will be passed electronically to my Bank/Building Society.

Signature(s)

Date (DD/MM/YYYY)

Banks and Building Societies may not accept Direct Debit Instructions from some types of account

This is not part of the Instruction to your Bank or Building Society

My Details

Name

☐ *Mr* ☐ *Mrs* ☐ *Ms* ☐ *Other (Please Specify)*

Address

Postcode

Donation Details

I would like to make a regular donation of £

☐ *Monthly* ☐ *Quarterly* ☐ *Half Yearly* ☐ *Annually Commencing*

01 / ☐☐ / ☐☐☐☐ *or*
15 / ☐☐ / ☐☐☐☐

Gift Aid Declaration

Please Gift Aid this donation and any donations I make in the future or have made in the past 4 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.

Please notify us if you want to cancel this declaration, change your name or home address or if you no longer pay sufficient tax on your income and/or capital gains.

☐ *Tick to apply*

T62

This guarantee should be detached and retained by the Payer

The Direct Debit Guarantee

- This guarantee is offered by all Banks and Building Societies that accept instructions to pay Direct Debits
- If there are any changes to the amount, date or frequency of your Direct Debit, Charities Aid Foundation will notify you ten working days in advance of your account being debited or as otherwise agreed. If you request Charities Aid Foundation to collect a payment, confirmation of the amount and date will be given to you at the time of the request
- If an error is made in the payment of your Direct Debit, by Charities Aid Foundation or your Bank or Building Society, you are entitled to a full and immediate refund of the amount paid from your bank or building society - If you receive a refund you are not entitled to, you must pay it back when Charities Aid Foundation asks you to
- You can cancel a Direct Debit at any time by writing to your Bank or Building Society. Written confirmation may be required. Please also send a copy of your letter to us.

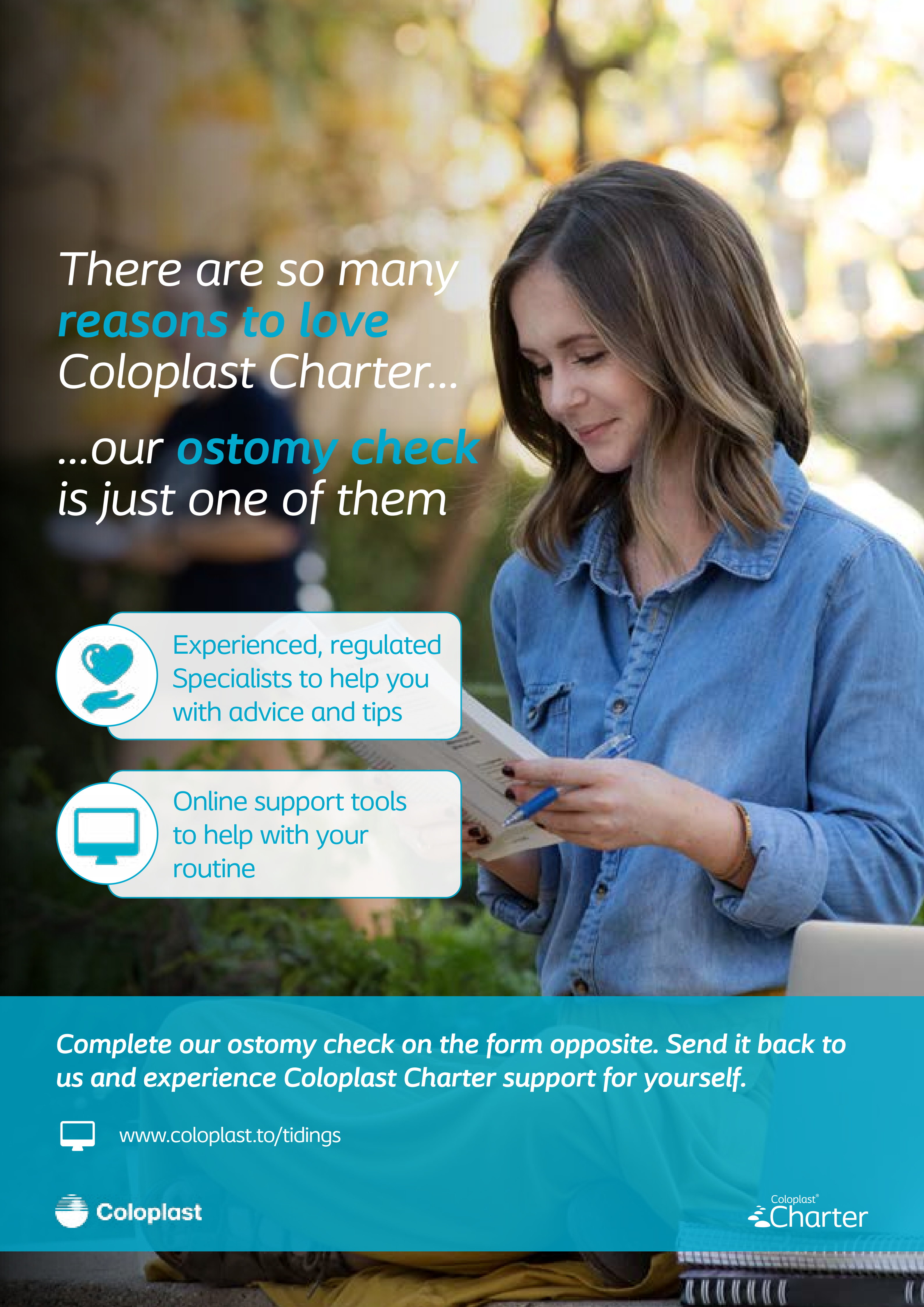
Colostomy UK

What will **your legacy** be?

Help us to support the ostomates of today and tomorrow by leaving a gift to Colostomy UK in your Will.

Colostomy UK have been supporting ostomates like you, their family members, and carers for over fifty years.

With your help we can continue to do so for many years to come. A gift in your Will can help to ensure that services like our 24–hour helpline and Tidings magazine continue, while allowing us to develop projects that support ostomates' mental and physical health, train more carers to support those that need it, and continue to campaign for a more 'stoma aware' UK. If you'd like more information about leaving a legacy to Colostomy UK please see the leaflet enclosed with this edition, or call us on: **0118 939 1537** or email: **info@ColostomyUK.org**



There are so many *reasons to love* Coloplast Charter...

...our *ostomy check* is just one of them

- Experienced, regulated Specialists to help you with advice and tips
- Online support tools to help with your routine

Complete our ostomy check on the form opposite. Send it back to us and experience Coloplast Charter support for yourself.

www.coloplast.to/tidings

Coloplast

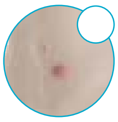
Coloplast® Charter

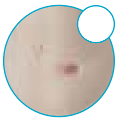
The Ostomy Check

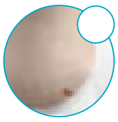
We understand over time your body shape and lifestyle can change, so it's important that you regularly check your stoma care routine, as well as ensuring that you are still on the best baseplate solution to fit your body shape. Why not take the Ostomy Check today to help you identify common issues such as sore skin, problems with adhesion and leakage?

Which best describes the area around your stoma?

Please tick in circles where appropriate


○ *Regular*
The stoma opening is above or level with the skin surface

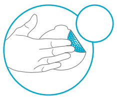

○ *Inwards*
The stoma opening is below skin surface or requires some support due to challenges on dipped areas

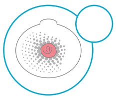

○ *Outwards*
The stoma opening is on curved body area or bulge.

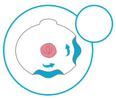
Do you have any adhesion issues?

Ensuring your product sticks securely to your body helps you feel secure, and prevents complications.
You can tick one or more issues.

○ *None*


○ *Insufficient adhesion when applying*

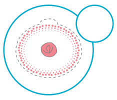

○ *Adhesive dissolves during wear*

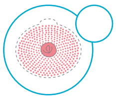

○ *Adhesive edges roll*

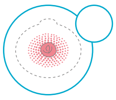
Do you have any skin irritation issues?

Your skin around your stoma should look like the rest of your stomach.
If not, you can tick one or more issues.

○ *None*


○ *At the outer edge of the baseplate*

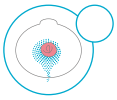

○ *Under the baseplate*

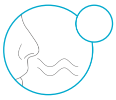

○ *Around the stoma*

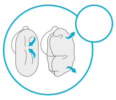
Do you have any pouch issues?

It is important that your pouch works for you and that you feel confident wearing it.
You can tick one or more issues.

○ *None*


○ *Leakage*

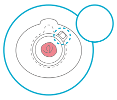

○ *Odour*

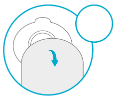

○ *Ballooning or pancaking*

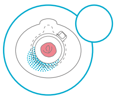
For two-piece appliance users only

It is important your two-piece works for you. Tick on any coupling issues you might have.
You can tick one or more issues.

○ *None*


○ *Coupling difficult to close or open*


○ *Pouch falls off*


○ *Leakage at coupling*

Would you like a member of our CQC regulated Telehealth team to call you to discuss the answers you have given above?**

Yes, please call me (tick as appropriate) ○

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Date of birth ______________________

Email ______________________

Date of Stoma Surgery ______________________

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#ActiveOstomates

active ostomates®

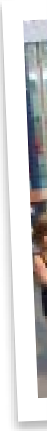
Five years and counting!

It's hard to believe that Active Ostomates has been running for five years! In this edition we're going to look back at what we've achieved, as well as looking forward to some new initiatives we hope will excite and get you moving!

Some years ago, we ran a quality of life survey in Tidings, aimed at understanding the impact of having a stoma on the lives of our readers. The responses to this revealed that many ostomates needed help and encouragement to get active again after surgery. Thus, Active Ostomates was born.

Grants from Sport England and Berkshire Community Foundation supported the project's launch and have gone on to help as Active Ostomates has developed. The first thing we did was to publish our booklet 'Active Ostomates: Sport and Fitness After Stoma Surgery'. Since then we have reviewed and revised it regularly. It's proved extremely popular: we distribute thousands of copies each year to ostomates and healthcare professionals. In 2017 it even won Highly Commended at the BMA Patient Information Awards.

The plan at the start was to deliver activities through stoma support groups. This worked well up until early 2020 when the pandemic hit. We began by piloting chair yoga in partnership with the East Berkshire Ostomy Group. Regular classes were held during the project's first year and were well received, with participants enjoying the focus on movement, breathing techniques and relaxation.



Evidence from the pilot allowed us to access funding from the Big Lottery Fund. We used this to support a broader roll-out in 2017, delivering chair yoga sessions in Kent, Bedfordshire, Buckinghamshire, Hampshire, Hertfordshire, and Essex, followed by the Midlands, Yorkshire, and the North East. We also trialled archery taster sessions in Milton Keynes and Crowthorne. By the start of 2020, chair yoga was still going strong with sessions running from Glasgow right down to Exeter!

While all this was happening the popularity of Active Ostomates was increasing too. We noticed that younger ostomates were also keen to get involved. This was very exciting, but it meant we had to get our thinking caps on, as chair yoga is generally more suited to the 55-plus age group.

2018 was our breakthrough year and saw the launch of Creative Minds art classes, Active Ostomates swimming, and our Team Colostomy UK Rugby League team. The success of Team Colostomy UK Rugby League has been covered in previous issues, however it's still worth mentioning the impact it has had in supporting ostomates to make the step back to playing contact sports, and in raising more mainstream awareness of Colostomy UK and in **#TacklingTheStomaStigma**. To find out more, have a read of Ed Rowland's story on pages 18-19.

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

Taking the plunge

Knowing that many ostomates are put off swimming by the thought of people staring at them and the fear of bag leaks, we decided that the best way to get people back in the pool was to try to remove these barriers. Hence, we decided to book out an entire pool and changing facilities.

Sheerness Swimming Pool in Sheppey, Kent, was the venue for our first two 'ostomate only' swimming sessions. There was no organised activity just the chance for ostomates and their families to have some fun.

The feedback afterwards was just what we hoped. One participant said: *"I had never been swimming with my boy and he is seven years old. Ever since I had my stoma, I lost confidence. Thanks to Colostomy UK we now have some great family memories."*

After the success at Sheppey, we went on to organise similar events in Newcastle, Gateshead, Durham, Leicester, Londonderry, Liverpool, and Windsor. Just before the pandemic it was the turn of Bristol, Nottingham, and Manchester. The aim to is to re-start swimming as soon as possible.

Art attack

"None of us were much good but that wasn't the point. We all had such a good time that we forgot why we were at the group in the first place."

Art has proven benefits such as boosting self-confidence and esteem, increasing cognitive stimulation, and improving dexterity and motor skills. It should also be fun and that's the overriding objective of our Creative Minds art classes.

After successful trials in Wycombe and Milton Keynes in 2018, we started a wider roll out of our Creative Minds art classes, in partnership with the social enterprise of the same name. 2019 saw ostomates from Glasgow, York, Newcastle, Gillingham and elsewhere get their creative juices flowing by enjoying activities as diverse as pottery, painting, and deco patch.

Accepting the challenge

Encouraging ostomates to be more active has also been the driving force behind our hugely successful challenge events: 50K Challenge (2018) and Stoma66 (2019).

The idea behind both challenges was to encourage people or teams of like-minded people to be more active on a regular basis, be it achieving a target of 50,000 kilometres or exercising for 66 consecutive days.

The two events together had over 1,000 participants, many of whom raised funds for Colostomy UK at the same time, which we used to support the continued growth of our Active Ostomates project.

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Lockdown blues followed by a boost

In March 2020 our plans for the year came to a shuddering halt.

We knew that shielding and stay at home guidance would have a negative impact on many people's mental health and ability to stay active. So, in April 'Active Ostomates: at Home' was born. We started by running online Mindfulness and Meditation classes, and art sessions. The reaction was so positive we added new activities during the year, bringing 2020 to a close by revealing our latest addition: 'Pop to the '80s Dance'. What better way to unwind than by bopping to Flashdance, Footloose or Fame!

So far 700 people have joined our online classes.the continued growth of our Active Ostomates project.

What's next?

Since 2016 over 5,000 people have taken part in Active Ostomates activities. It's something that we are very proud about!

But while it's been great to look back, our focus is on now and the future:

Active Ostomates: at Home

The week starting June 7th will see the return of our yoga, Mindfulness and Meditation, and chair yoga classes, and a brand new 'Pop to Movies & Musicals' dance class. To find out more or sign up for any of the classes just visit the Active Ostomates home page on our website. **colostomyuk.org/active-ostomates/**

April saw us launch two new classes: zumba and family crafts. They will also be returning later in the year. To keep up to date on all our classes why not sign up for Colostomy UK's regular e-newsletter **colostomyuk.org/support/colostomy-uk-e-newsletter/**

Rugby league *Returns!*

We're hoping that our Team Colostomy UK Rugby League Team will be back on the pitch soon. We're always looking for new players, volunteers, and supporters. To find out more email **Giovanni.cinque@colostomyuk.org.**

Community sessions

With the easing of lockdown restrictions stoma support groups will soon start meeting in person again.

As this happens, we'll be looking to reintroduce our swimming, Creative Minds art and chair yoga classes, with the potential of some new activities too! For the latest updates go to **colostomyuk.org**, sign up for our e-newsletter, or keep an eye on Tidings.

In 2026 when we're writing about the 10th anniversary of Active Ostomates, I really hope that 'Step Up for Stomas' will be remembered as one of the highlights. What's **'Step Up for Stomas'**? See page 36.

dear nurse

Mark Johnson
Clinical Nurse Specialist – Stoma
Fittleworth Medical Ltd

Pancaking – **hints and tips**

Formation of a stoma brings with it many challenges. Some of these challenges can cause more worry than others.

During my time as a stoma care nurse specialist one of the questions that is asked most frequently is why does the stool sit on the back of the pouch and how do I stop it? In this article I'll talk to you about the reasons and possible treatments for it, if and when it occurs.

Pancaking of the stoma may not be a term you are familiar with or have experienced. Hopefully it's something that you won't experience, however it can be very common. Pancaking is used to describe when stool leaks out under the flange of a stoma appliance after it has been applied to your skin. It is more common in a colostomy patient but can also happen to patients with an ileostomy (a wetter type of stoma). It can form a disk of thick stool, looking very much like a pancake on the back of the pouch.

Why does this happen and what can I do about it?

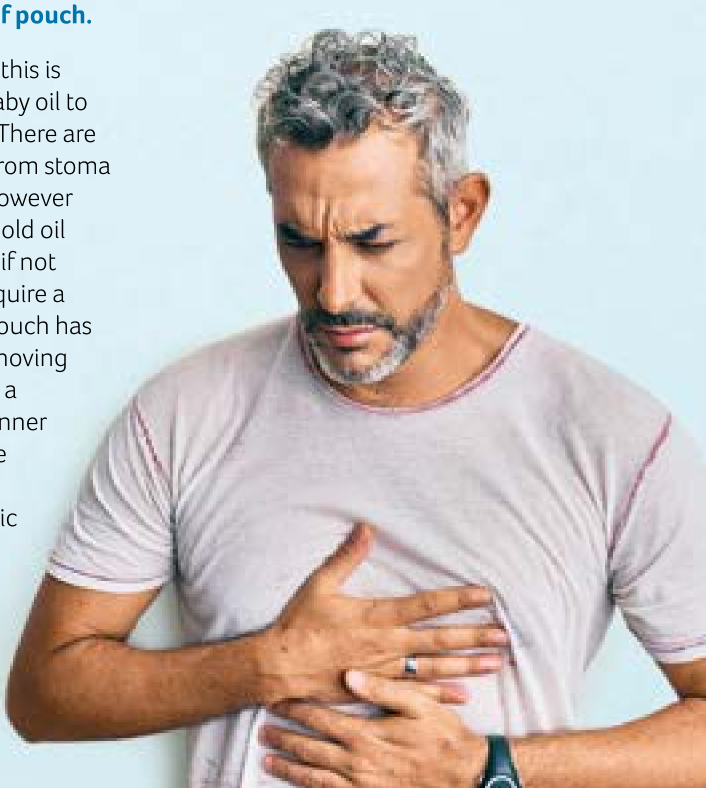
Pancaking can happen for a number of reasons, most of which are easy to solve. However, if it is a recurring problem that the simple tips below don't sort, then you should contact your stoma care nurse.

By far the most common reason is that the pouch has created a vacuum due to the filter being ineffective or becoming blocked with stool. This can happen regardless of how often the pouch is applied, the technique used or the manufacture of pouch.

- A really simple trick with this is to apply cooking oil or baby oil to the inside of the pouch. There are lubricant gels available from stoma pouch manufacturers, however most of the time household oil does the job just as well, if not better- and it doesn't require a prescription. Once the pouch has been cut (and before removing the backing sheet) apply a tablespoon of oil to the inner plastic layer on the inside of the pouch. This will lubricate the inside plastic layer, allowing stool to slide down the inside of the bag.

The stoma may be flat/flush to the skin, causing the inside of the pouch to stick to the stoma surface.

- Applying oil as mentioned above can help with this also, but another tip is to blow air into the pouch prior to applying to the skin. Although the filter will remove the air over time, it should be there long enough to stop the pouch getting too close to the stoma.
- Another tip is to place a rolled-up ball of toilet roll to the base of the pouch. This should be dropped into the pouch prior to it being applied to your skin. This will act as a bridge between the stoma and the pouch, hopefully stopping the pouch sticking to the stoma.



The stoma may be retracted back or lying in a crease that causes the stool to collect under the pouch and not drop in through the pouch hole. This can be for a variety of reasons, including post-operative weight loss/gain, herniation or applying the pouch with creases in place.

- This is a tricker reason to advise on, and really you need to be reviewed by your stoma nurse, especially if this is a regular occurrence.
- Your stool may be very sticky and the pouch clings to it as it is passed from your stoma.
- A review of your diet may help with this. Your stoma care team may have specific advice depending on your medical history. They might also signpost you to further information websites or leaflets. Increasing your fluid intake may help (especially in hot weather), although this should be increased with caution.

Medication can also be another cause of pancaking. Medication such as iron can cause the stool to be sticky and discoloured.

- Unfortunately, it may not be possible to change the medication you are on, but it may be worth a talking to your GP, stoma nurse or the healthcare professional who prescribes your medication to see if any alterations can be made.

Pancaking of the pouch and your stoma is a very common issue and any of the tips above may be universally applied to the situations that are mentioned. And don't forget: even through the continuing pandemic your local stoma team or nurse are still on hand to offer help, tips, advice, and treatment.

Colostomy UK

Looking for online **support?**

Our private Facebook group 'Colostomy UK Support Group' has over 9,000 people and it is a safe community in which you can find support from others living with a stoma. It's not just for those with a stoma; friends, family and healthcare professionals are welcome too.

There is plenty of support available via our website, **www.ColostomyUK.org**. Not only is there a wealth of information, we also have **'Live Chat'** support available 09:00–17:00 on weekdays.

Don't forget, if you can't find the support you need online, you can call our Stoma Helpline (**0800 328 4257**) 24-hours a day.

www.ColostomyUK.org

Find us on
Facebook

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Step UP FOR STOMAS

Will you Step Up for Stomas in September?

Colostomy UK are going to 'Step up for stomas' this September and we would love you to join us!

We're inviting you to walk, run, jog, skip, crawl or hop 160,000 steps in the month of September to help you get more active, and to raise funds to help us better support ostomates and those who care for them.

Why 160,000 steps, we hear you ask?

There are 160,000 people in the UK with a stoma so we'd like you to take a step for every single one of them.

You can undertake the challenge on your own or combine your steps with others to form a team and reach the target together. It doesn't matter if you're active already or just looking to get fitter; either way, taking our Step Up for Stomas challenge can only be a good thing!

Step Up for You

It's no secret that exercise is good for both your physical and mental health. Walking can help your mental health by reducing anxiety, depression, and a negative mood. It can also boost self-esteem. Walking and running are some of the easiest ways to get more active and become healthier and you don't need lots of equipment or a gym membership! As long as you have a trusty pair of trainers or walking shoes, you can Step Up for Stomas and start getting fitter.

The NHS states that adults should do some type of physical activity every day. Any type of activity is good for you and the more you do the better. To cover 160,000 by yourself, you need to do about 5,300 steps a day, which is about 2.5miles. This equates to about 50 minutes of walking or 30 minutes of running each day.

Moderate aerobic activity such as a brisk walk can:

- **Burn calories**
- **Strengthen the heart** (walking at least 30 minutes a day, five days a week can reduce your risk of coronary heart disease by about 19%)
- **Lower your blood sugar**
- **Ease joint pain**
- **Boost immune function**
- **Boost your energy levels**
- **Improve your mood**

Step Up for Ostomates

Colostomy UK is a self-funding charity so every £1 we raise really matters!

As part of this challenge we would also love it if as many of you as possible could try to raise £160 or more.

All funds generated will go towards supporting our key projects and services including our 24-hour Stoma Helpline, our new befriending service, and the continued production of Tidings magazine. It will also allow us to train more volunteers, encourage more ostomates to get active, and help us to campaign for a more stoma aware United Kingdom.

How to sign up

- To take part in 'Step Up for Stomas' you can register online at **colostomyuk.org/active-ostomates/step-up-for-stomas/** There will also be a pull-out in the next issue of Tidings.
- We will then email you our activity guide full of loads of hints and tips to help you reach the160,000 step target.
- We'll also send you details of how you can set up an online fundraising page or request a sponsorship form.
- The first 50 registrations will receive a complimentary pedometer to help you count those 160,000 steps.

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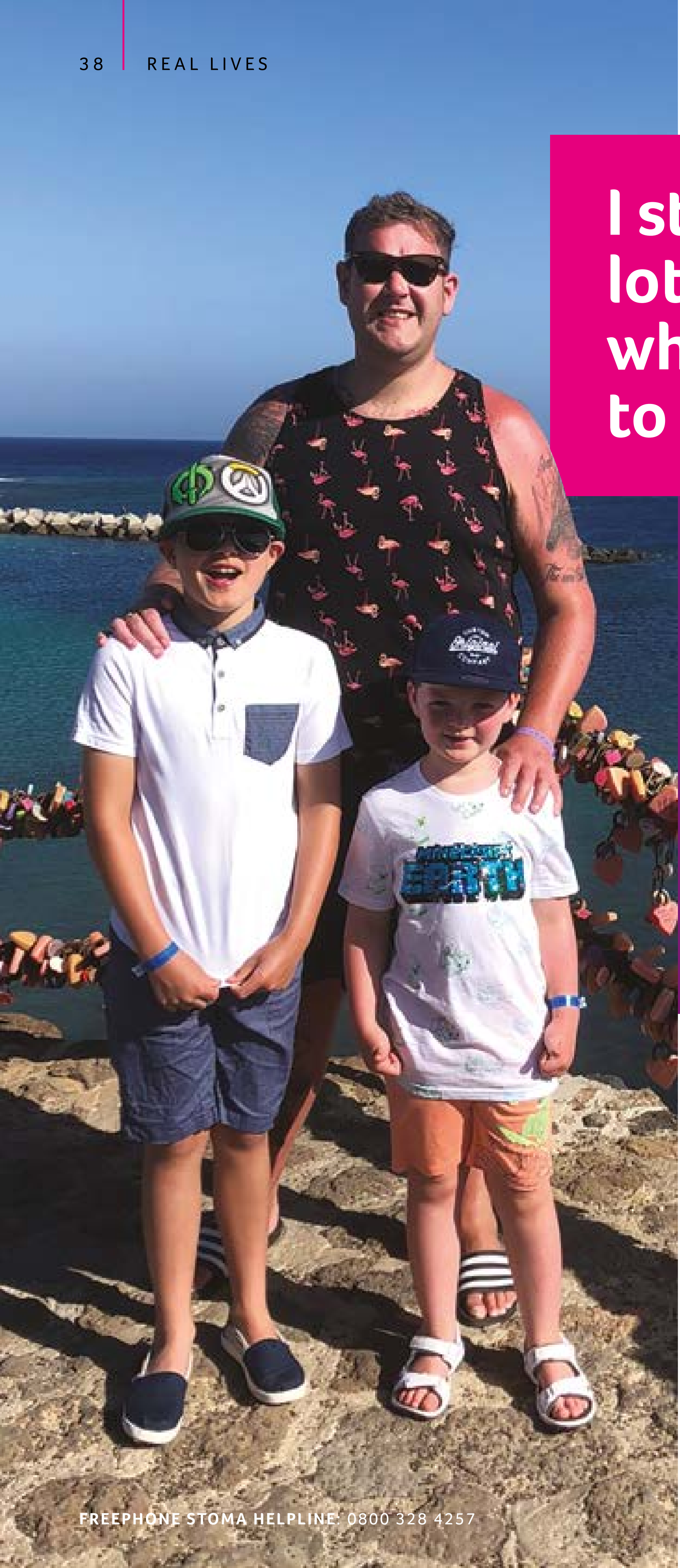

I still carry a lot of guilt when it comes to my illness

BY JOHN BIGLAND

Editor's note:
In this raw, courageous article we learn of a young man's struggle to come to terms with life after surviving cancer. It is sad but also life affirming.

I am 36 years old and live in Urmston, Manchester. I'm a criminal investigator for the UK Government, investigating large-scale frauds, before arresting and questioning suspects. I live with my fiancé Gemma and my stepson Alfie. I have a 6-year-old son, Sonny, who lives with my ex-partner (who I will call Sally*) in Dublin. Gemma and I are due to marry shortly. I have a colostomy and urostomy from rectal and bowel cancer. At the moment I also have a nephrostomy** as one of

*this is to preserve anonymity. **A nephrostomy is an opening that is made between the kidney and the skin on your back. It lets urine drain from the kidney.
For more information visit https://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/nephrostomy

my kidneys is blocked. Like any lad my age, I watch football, enjoy fishing and having a few pints.

A year before my diagnosis (January 2015) I moved to Dublin to be with Sally and my little boy who was 18-months old. Sally struggled with post-natal depression and my absence was difficult for her. I travelled over to see them monthly until I could arrange a permanent move. We met in Benidorm and did the long-distance relationship thing for two years before finding out we were pregnant. I was working as a prison officer prior to moving over. I had a few jobs in Dublin before being employed as a search officer in Dublin Airport Security. I made a few friends, joined a football team, and tried to settle in.

My symptoms started in March 2015, just little things, like not feeling I had emptied when I went to the toilet and having to push a lot. I put it down to the stress of moving and having to do exams for my new job. But as things weren't getting better I visited my GP, who referred me for a sigmoidoscopy. As Sally worked at the hospital, I was able to move the appointment from January 2016 to November 2015. The week before it I had the bad news that my step mum had died of post-cancer complications. She and my dad had been together since I was two and we were very close.

At the sigmoidoscopy, the nurse saw a tumour. She rang for a surgeon immediately. I was out of my mind at this stage, bawling my eyes out with panic and fear. He told me I'd have to stay in for tests. I had never been in hospital before apart from the odd football injury. I had Sally and her family, but being in Dublin, not my own family. I was in hospital for a week having tests, then the colorectal surgeon, Mr O'Rhiordan, met with me, Sally, and her mum. He confirmed I had cancer and would need a permanent colostomy. Sally and her mum cried. I felt numb. All I wanted to know was that I wasn't going to die, which he couldn't tell me. I was distraught thinking I might not see my son grow up. I was told that had the sigmoidoscopy taken place on the original date, it would have been too late.

Deciding where to have treatment was tough. Who did I want to see me suffering in hospital, my family or my fiancé and son? I decided Dublin. I started chemotherapy and was booked in for radiotherapy. Breaking the news to my family and friends was horrendous, especially as I was in another country. My parents and grandparents were devastated. I arranged to fly back to Manchester. Days after getting out of hospital, Sally and I went to the cinema to try and take our mind off things. Upon leaving the cinema I found a message on my phone saying my dad had died. It was unexpected and floored me completely.

Being back in Manchester was upsetting. My family tried to rally round but I was mentally not there. I was trying to plan my dad's funeral with this huge cloud over me. I carry a lot of guilt towards my dad. He died grieving his wife and devastated by my diagnosis, knowing I might not survive. On the night of his funeral I flew back to Dublin to start my radiotherapy the next day. Sally came with me. The radiologists were great, but it was still scary having my pelvic area lasered.

The day after my first session a nurse took me to a side room where I was surprised to see Sally. She told me that my grandad had died. Again, it was a massive shock. I had lived with my nana and grandad from the age of 11 until I moved to Dublin. My grandad was a more influential father figure than my dad. The family agreed to delay the funeral until after my radiotherapy. I was in agony with the side effects. Going to the toilet was like passing sandpaper and often left me in tears. I flew back to Manchester to bury my grandad late January 2016. I have a lot of hatred towards cancer. I was so worried about my cancer I couldn't grieve properly for my dad and grandad and I still haven't really.

I saw Mr O'Rhiordon in February. He told me the tumour had grown into my bladder and this would need to be removed to have a clear margin, meaning an irreversible urostomy too. It's hard to even recall how I felt. He explained a full pelvic clearance was necessary: removal of my anus, rectum, bladder, prostate, and some bowel. The loss of my prostate meant I would never be able to have erections again without injecting my penis. As a man in his 30s this was one of the biggest things for me to get over. I had already had to have sperm frozen prior to my radiotherapy as I was told I wouldn't be able to have any more children afterwards. As a couple we were devastated because we wanted more. Me and Sally had a weekend away to give it one last hurrah before surgery.

My surgery was in April 2016. I was beyond frightened. I didn't sleep much the night before. I made a video for Sonny saying goodbye as there was no guarantee I would wake up.

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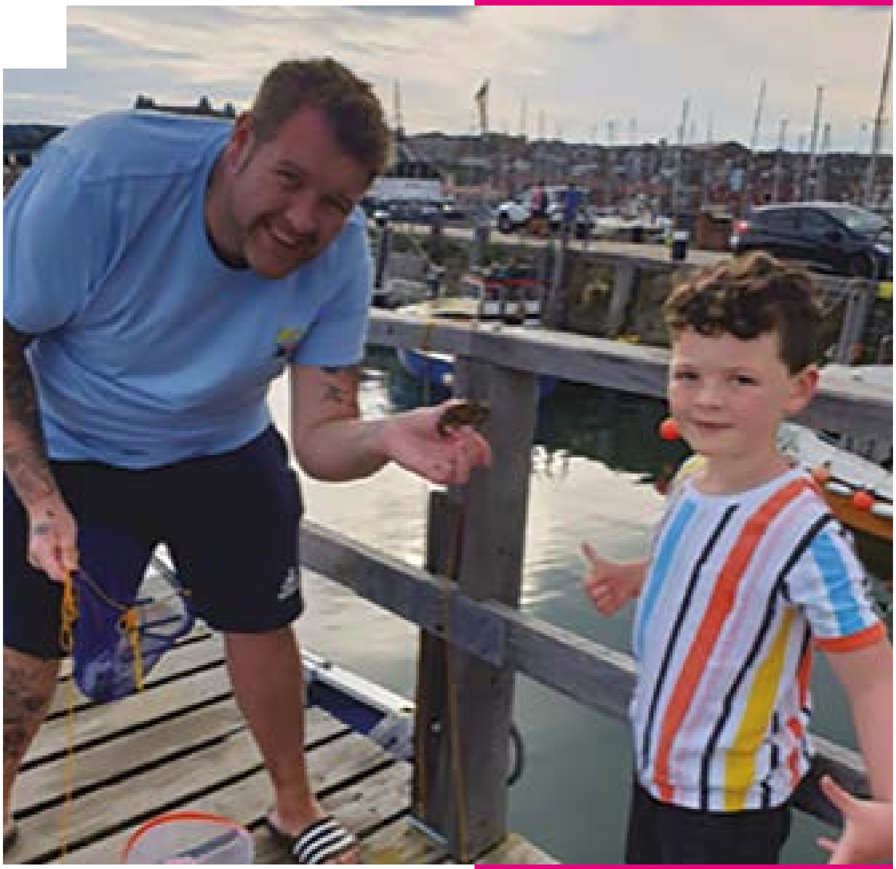
My surgery was in April 2016. I was beyond frightened. I didn't sleep much the night before. I made a video for Sonny saying goodbye as there was no guarantee I would wake up. I came around five days later. I spent two weeks in hospital recovering and getting help with being steady and walking again. The surgery and subsequent infection caused me to lose some feeling in my feet.

I was only out of hospital a few days before being re-admitted with an infection in the wound on my backside. I had to wear a vacuum dressing and see wound management nurses daily for six months. This was on top of getting used to my new stomas and bags. My colostomy was fine, but about two months later I started getting urine leaks. My stoma nurses tried everything to no avail. It was a mixture of the spout not being long enough (it had collapsed internally) and my wound being close to the stoma site causing a crevice which the stoma team couldn't get a seal on.

I started my second bout of chemotherapy in late 2016. They gave me the strongest stuff they could as they said I was young enough to take it. I was also given a slow release one. Other than wiping me out for days afterwards, I was lucky. I had no other side effects. Sadly, me and Sally were in a bad place. I was unwell, leaking everywhere and my penis didn't work. I felt completely emasculated. We tried being passionate but there's nothing like injecting your penis to kill the mood, plus the Caveject injections didn't really work. We were drifting apart. Sally had her own problems too. She will have her own version of events. Mine is that she was only just recovering from post-natal depression and then her fiancé was given this devastating news. Not only was she looking after me but our son as well. At nearly three he didn't understand what was happening. She turned to drinking secretly to get through it. I tried my best to help where I could and maintain the relationship, but I was so ill. We tried counselling and talking, but to no avail. Sally eventually had a breakdown and was admitted into psychiatric care.

I made the heart-breaking decision to return home on the basis that having a break from me Sally would hopefully get better. Unfortunately, she wasn't prepared to give us another go. No one cheated, it was just two people put under unbearable pressure. All our future plans: more children, mortgage etc. were destroyed in the blink of an eye. I will always love Sally and her family for what they did for me. We still have a very strong relationship including my family and hers. I see Sonny at least once a month and we FaceTime every day (especially important with Covid-19 as I haven't seen him since August). I stay sometimes at the family home and Sonny comes to Manchester during school holidays.

Adjusting to life back in Manchester wasn't easy. I was back in my childhood bedroom with two bags, one of which was leaking, a huge scar, single, with a non-functional penis: not much of a prospect for the women of Manchester. I dated a few girls, but it never got to the intimacy stage because of my lack of body confidence and my 'equipment' not functioning. That changed when I met Gemma in October 2017. She put me at ease about everything. We were open about everything from the start. She took me on knowing how broken and damaged I was and saw past the scars and bags. I love her so much, not just for this but for being there.



Further scans showed my stoma had collapsed further and the leaks were uncontrollable. My urostomy was eventually revised in December 2017. I felt bad for Gemma as we hadn't been together long and she was subjected to this. It meant more invasive surgery on my pelvis. More of my bowel had to be removed, including my ileocecal valve. This has subsequently affected the transit time and consistency of my colostomy output. My stool has been watery ever since and I go very frequently, sometimes 20 times daily. Consequently, I get dehydrated and drink more, which means more output. It's a vicious cycle. I now have a problem with digestion and frequent blockages to deal with.

Post-op recovery wasn't bad. I started to research what could be done about my penis. The urologist outlined some options unavailable in Ireland. Me and Gemma tried the injections but again they didn't work. I was referred to a specialist in Harley Street, to see about having a penis implant. This required hollowing out my penis and inserting two inner tubes. These are connected to a reservoir which, when pumped from the attachment in the scrotum, fill with saline causing an erection. I agreed this was the best option and had the surgery in January 2019. Post-op pain was horrendous, but I had Gemma looking after me. Once recovered I was overjoyed. I had my manhood back and could have sex again. Gemma didn't complain either.

I still have regular checks with my surgeons and stoma nurses. They do a fantastic job. Me and Gemma are also trying for a baby.

I also felt well enough to consider going back to work. I returned to the prison briefly but only in a support role, which wasn't the same. I then passed the selection process for the job I do now. With two bags it has its pitfalls, especially when arresting people and getting into a physical altercation and placing them in handcuffs! Work is very supportive of my condition. I have been honest with them from the start. I still have regular checks with my surgeons and stoma nurses. They do a fantastic job. Me and Gemma are also trying for a baby. We have encountered problems meeting the criteria for IVF funding as we already have children but have put forward a case which will hopefully be successful. Maybe we will be blessed.

Writing this has shown me how much my brain has protected me from what I've been through. I can't remember all emotions nor recall everything said. Sometimes I catch myself daydreaming 'what if?'. I still carry a lot of guilt when it comes to my illness. I think about the upset I caused my family and the effect on Sonny. I wonder if Sally would have been as ill as she was. I think about all Gemma has put up with. I know this is silly as it wasn't my fault. My cancer originated from bad luck not poor lifestyle choices. I've had counselling, tried mindfulness and anti-depressants but I still can't shake it off yet. The one huge positive is that, thanks to all the healthcare professionals, I'm alive. All being well, I have a long life ahead. I will have more children and see Sonny grow into a man.

I hope my story helps someone in a similar position. After my diagnosis I made the mistake of turning to Google. The cancer I had is extremely rare in young people, so the statistics I found didn't apply. They just worried me. Thanks to social media I'm discovering that the stigma of having bags isn't what it used to be. I'm very happy to contribute towards dispelling the untruths. If having bags and scars means I'm alive then they should be celebrated, not covered up. It might not be pretty to look at, but it shows what I've been through and that I'm still fighting.

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Let's talk about sex

SUE LENNON

Sue Lennon
Psychosexual
Therapist

I am a Psychosexual Therapist (sex therapist / sex therapy for short) and I work with people who have experienced negative sexual consequences from life changing illnesses and treatments for those illnesses. I know that IBD and bowel and bladder cancer (and their treatments) have a huge sexual impact and I support and have supported clients following stoma surgery. Having been a Tidings' reader for quite a few years now, I have, with my professional eye, noticed how rarely the subject of sex turns up in the stories of contributors. This lack of discussion is not just here in Tidings. Sadly, it is often missing throughout the healthcare journey, from pre-treatment information giving and the consent process, to discussions about aftercare, be this related to drugs, chemotherapy, radiotherapy or surgery. I'd really like to change this. I know that people are missing out. They are suffering sexually but don't know who to ask, or how to ask, or even if they are allowed to ask.

What do I mean when I say: talk about sex?

I think it is worth pointing out early on that when I talk about sex, I am talking about the whole experience of the sexual 'self'. Many people think about sex as just intercourse but there is so much more to a sex life than that! When I talk about sexual challenges, I mean everything from negative feelings about your body to whether your sexual confidence has been affected, from loss of intimacy to a changed social life. Do you still swim, hug, dance, and eat out, for instance? What is different now and why?

I'm also interested in whether your romantic partnership is different, whether you can talk about your feelings and fears together, discuss expectations, problem solve. If you were sharing a bed before, are you sharing a bed now? Are you able to ask for your sexual needs to be met even if that means you are not ready for intercourse, but you really would like a proper cuddle? If you are single, has your stoma changed your view of future relationship possibilities? How are you approaching the dating game?

And then there is the sexual function side of things – is everything in 'working order' post-treatment? Do fistulae or pelvic pain stop lovemaking, or do you struggle to get and keep an erection perhaps? And of course, for younger clients, has the potential impact on fertility and on reproductive decision making been thoroughly discussed and action taken if required?

The work of a sex therapist requires such a lot of curiosity!

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Why is the sex topic tricky?

I often speak at conferences about the topic of sex and illness. I have spoken to thousands of healthcare professionals about how to approach what they usually believe to be very delicate conversations about terribly private matters. I have heard from specialist nurses working with the nomadic Sami people of northern Scandinavia, those who support disabled teenagers and their families, from adults with learning difficulties, people with spinal cord injury and so on. Even after all my years of practice I still find it interesting hearing the thoughts of healthcare professionals on the subject AND getting the patients' perspectives. You ostomates are such a wide range of individuals, with a variety of disease processes preceding your stoma formation.

You are also culturally different, come from various religious backgrounds (including secular), may be heterosexual or not, partnered or not, and you span the ages, from new-born to ... beautifully matured. Our health professionals are also a diverse bunch. We are treated by doctors from a huge range of countries and creeds, supported by nurses of every skin tone and of course they all come with their own family and cultural backgrounds too. It's no wonder that things get tricky when it comes to **'sex talk'**. Diversity and embarrassment and assumptions along with fear of offending all conspire to make discussions about the sexual impact of disease and treatment feel too hard to have. Healthcare professionals are interested however, but they don't always know how to ask, and patients don't always know how to tell.

How can we change matters?

Challenging the lack of discussion about sex in healthcare is one of my missions, and I feel that after a long time of shouting and feeling quite alone, things are about to start changing. This problem is not unique to stoma care. Many specialist services miss out the sexual impact of illness. It is possible that things need to change at nurse and medical training levels, so that a strong foundation can be built ready for later on, when people go through specialist training – increasing their confidence to assess and address sexual matters. It would also be great if care teams knew how to refer to a sex therapist, should they identify a patient who requires and would like specialist input. But I think what we can really change is getting the patient voice heard. Ostomates can be powerful and together your experiences can initiate change by demonstrating that sex matters.

But what does a sex therapist do?

First and foremost, sex therapy is a talking therapy. No-one is asked to undress or do anything sexual in the therapy room! Usually a therapist will offer an initial appointment to give you time to talk about whatever sexual concerns you are having and also discuss with you what you can expect from therapy and what your goals for recovery might be.

Sexual problems are often a combination of physical and psychological, so a keen interest will be taken in the interplay between the two sides to the problem. For instance, a person who now suffers painful intercourse could make it nearly impossible for their partner to get close. They could be rather snappy or cold towards their partner who has no idea what is going on and may feel very hurt and rejected. Both partners may secretly crave a cuddle but do not know how to ask: one for fear of that cuddle leading to something more…and the other for fear of getting it wrong and having a row to deal with. A sex therapist can help you unpick all of that and over a number of weeks will give you exercises to do at home to help move you towards whatever goals you set for your recovery.

Sexual intercourse does not have to be the goal, however. The goal is always that of the client's, not the therapist, and intercourse is only one item on a long menu of sexual possibilities! Some people want help with sexual function problems – loss of erection or vaginismus (an involuntary spasm of the vagina which can make penetration impossible) – while others want help with social and sexual confidence or loss of libido.

How can you find a sex therapist? Some hospitals have a sex therapy service though sadly these are becoming rare. If you feel that you may need help then the first thing I would advise is that you tell your stoma care nurse or consultant that you are having difficulties and ask if there is a sex therapy service in your hospital. If you have been discharged from the hospital service, then your GP or practice nurse should be able to make enquiries for you. If there is no NHS sex therapy service locally, then you still have a couple of options, though you may have to pay.

Many RELATE centres offer sex therapy and you can self-refer to those, usually just with a phone call or email. The therapists may not know much about your stoma journey, or what having a stoma means, but you can explain all that has happened and educate them a little while they help you reach your recovery goals.

Alternatively, you can look to the College of Sexual and Relationship Therapists website, where you can learn more about sex therapy and use their 'find a therapist' facility. You put in your postcode and it shows you where local therapist can be found. Many therapists are working online nowadays, so distance doesn't have to be a problem. Both NHS and private therapists are listed.

Or, you can look at my website **www.suelennon.com** and drop me an email. I'd be really pleased to hear from you.

Sue Lennon was an oncology nurse for 28 years, ending her career with 14 years as a Macmillan Urology Nurse Specialist. It was during this time that her interest in the sexual impact of illness grew and she trained to be a psychosexual therapist in 2008-10. She is now based in France from where she runs a psychosexual rehabilitation service online, regularly teaches on stoma care nurse education programmes and speaks at international conferences on the subject of assessing and addressing the sexual impact of illness, ostomy or spinal cord injury. She is also a mad keen vegetable gardener.

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16 years and more than 20 surgeries

Senior Sister Laura Plant talks about her 16-year battle with IBD and Crohn's Disease and what she has learned along the way.

LAURA PLANT

Good health is one of those precious things that we don't recognise or appreciate until we no longer have it. It is also something that as a 17-year-old A Level student I didn't really think about too often. That was until April 2005. I was on a break from school and noticed that I was experiencing stomach aches more frequently, and it was more than period-like pain. There was blood whenever I went to the toilet. The bleeding got worse, the stomach pains became almost constant and then came the unruly bowel movements that interrupted my lessons, kept me awake at night and eventually left me fearful of leaving the house.

My symptoms were quickly dismissed by my GP. As a young adult, being told this by a healthcare professional instantly cast doubt in my mind and made me wonder if my experiences were nothing more than a figment of my imagination. I started to think that perhaps I was creating the problem myself. I somehow managed to keep going to school and preparing for my final A Level exams. I was desperate to finish and fulfil my dream of becoming a midwife. After forcing myself to carry on for another week, I couldn't take anymore, my body was giving up. I took myself to bed one Friday night and didn't leave it again until the following Tuesday when I was taken to my local A&E department by my parents. Pale, weak and barely able to stand up, I was immediately admitted to the paediatric assessment unit where I was put on a drip and given medications through a cannula in my arm.

The next few weeks were a blur. I remained in hospital for four weeks in total, where I was eventually diagnosed with Inflammatory Bowel Disease (IBD).

I had no clue what this meant, or what would be in store for me over the coming weeks. I was pumped with steroids and pain relief. The pain was so bad that I would throw up every time I sat on the toilet. After a particularly bad weekend and a few blood transfusions, I made the choice to have surgery. The next day I met my surgeon, and to this very day I still have the pleasure of being her patient. When asked when the surgery would be, she said it would take place the very next day. I felt an element of relief that my pain and suffering would soon be over. I met with the most wonderful stoma nurse the next morning who marked me for my stoma and answered any last questions. That afternoon the trolley came to fetch me for theatre. I cannot remember much of the next two weeks. I lost a lot of weight, I had to learn to walk again, and then learn how to take care of my new stoma. I took it in my stride and was just happy that I was pain free.

A few weeks after coming home, I turned 18. I was so grateful to have reached this milestone birthday. If I hadn't had the surgery when I did, it would have been a very different story. I was later told that my colon was on the verge of perforating. It was just as well that I was taken to theatre when I was. A-level results came out that summer and, unfortunately, I didn't make the grade to become a midwife, so I took some time off to figure out my next step.

I applied for my nurse training later that year and got a place to train the following year. I was happy to be living my life. The first 18 months of my training were pretty uneventful, then in Autumn 2007 I had my J-Pouch. When I had my stoma formed, my rectum was left in place, but this had seen better days. I therefore found myself in the position of either having this removed and ending up with what many refer to in the stoma community (me included) as a 'Barbie Butt', or try a J-Pouch. My surgery was a success, but I lost my safety blanket of a stoma in that op. I stayed in hospital for a week and then the challenge of training my bowel began. The early days were fine, I went back to university after about a month, and continued my placements. However, things didn't settle. I was vomiting after eating, which led many people, including family, to think I had an eating disorder. My weight plummeted to five stone 12lbs within six months, and things started to affect me mentally too.

People would stare in the street, the rumours were relentless, but I stayed focused on my nursing, completed my training, and qualified as a registered nurse in 2009.

Not long after qualifying, I started to have issues with abscesses and pain. After a number of minor surgeries, I was found to have a few fistulas. The abscesses kept reappearing, and then one afternoon while at work I started to bleed. This bleeding was profuse and continued for four days. I was admitted to hospital and received in excess of 12 blood transfusions, but to no avail. I was rushed to theatre in the middle of the night, close to losing both my J-Pouch and my life.

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My surgeon saved me again. I recovered, started to gain weight, and began to enjoy life again. Between then and around 2012, I was essentially 'okay'. I had a few minor ops to check my pouch, but nothing too intense. Unfortunately, in mid-2012 I was found to have large ovarian cysts that were affecting my daily life. Another open surgery was booked in, this went smoothly, and I was back at work in super quick time.

Fast forward to 2015, the fistulas were multiplying, and I was spending more time in the operating theatre than I wanted to. A new diagnosis of Crohn's Disease was made. This might sound strange, but it didn't have as much of an impact on me as you might think. It was the missing piece in a ten-year puzzle. Ultimately it meant I could get the help I needed and avoid clocking up any more frequent flyer miles in the operating theatre! I commenced immunosuppression therapy in the form of Infliximab infusions and Azathioprine tablets. My immune system disappeared (which is a bit risky when you're working as a nurse surrounded by all kinds!) but despite living dangerously each time I was at work, I started to feel better and 'well' again. This, however, was short-lived. Within 12 months of starting this treatment, I was back paying a visit to my favourite operating theatre to have my J pouch removed, and a permanent ileostomy formed.

It was a smooth recovery and I felt well almost instantly, which is why I have never questioned my decision to go ahead with this surgery.

> **After losing so many years too ill to live a full life, I was determined to make up for lost time.**

How are things now?

I am a senior sister in the same hospital where I have had all of my operations and treatment. I am currently studying for a Master's degree in nursing and busy planning lots of adventures for when Covid-19 lockdown restrictions have eased. As with anyone who has been unfortunate to have had in excess of 20 surgeries, I am dealing with some ongoing complications. As you would expect, my mental health has at times suffered too. Talking through things has really made a difference to my outlook on a lot of these complications. My next step medically is to focus on my fertility options. My ultimate goal is to become a mother.

What has the last 16 years taught me?

Lots of things actually: how to be resilient in difficult times; with every bad day you will get a good day; everything happens for a reason; and, most importantly, it's okay to be a bit different. No one ever made a difference by being like everyone else.

Your letters and emails

Editor's note: It was lovely to receive lots of emails and letters about the last edition of Tidings, particularly as they were all so positive! Here is a selection, as well as a word search for all you puzzlers out there. This was submitted by Dave Smart who, if you recall, sent us a crossword a few editions ago.

Word Search

A	C	D	I	E	T	T	S	G	N	I	D	I	T	S
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O	F	T	M	S	X	A	Y	E	S	C	D	O	M	H
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ABDOMINAL
ADHESIVE
BAG
BAG FOR LIFE
BARRIER
BELT
COLON
CONSTIPATION
CONVEX
CREAM
DEODORISER
DIET
DOCTOR
FACEBOOK
FLANGE
FLATULENCE
GASTRO
IRRIGATION
KEY
NHS
NURSE
STOMA NURSE
SWANS
TIDINGS
TRUSS
VELCRO
WEBSITE

Dear Editor,
Having read the letter 'How Green is Your Bag' in the last edition I thought I would write my comments.

My colostomy was formed in May 1990 and for years I always emptied my bag and re-used it without problems. It seemed obvious to me that if my 'poo' were solid it could be emptied, and the bag re-used. I use ConvaTec bags and flange, always having been given these from the start.I had no trouble whatsoever until the bags changed, now having what seems to be an inner plastic bit.

I was really struggling with this new bag design and eventually spoke to my local stoma department at Bath Royal hospital.

They explained that the bags are meant for single use and that to help me get a seal and fix the bag properly to use a lubricant.

What a waste of bags. I now find I have to throw away any bag that I use lubricant on, no matter how little 'poo' is in the bag as lubricant makes it impossible to re-use.I am very green usually and hope that the bag makers will soon go back to how they were before. That way I can hopefully flush the contents and re-use the bag for at least a day. Progress was not good in this case! *Regards, Mrs M Rice*

Hi,
Five Star Care from Specsavers
I thought it may be useful to let you know what happened to me recently as it's always great when people support you when you are in need.

I had an eye test booked at 9:30am. I have a colostomy and on the walk to the branch I had an upset stomach which meant my stoma bag became

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full of liquid. As you can imagine this was quite distressing. I arrived just before the appointment and explained to Charlotte at reception that I was having an emergency with my stoma bag and that I quickly needed to go to the public accessible toilets in the Sovereign Centre in Boscombe.

Charlotte saw my invisible disability badge and me holding my bag and without hesitation said to go with her and she took me to the staff toilet in the branch.

Afterwards while I was waiting for my eye test another member of staff came over to ask if I was okay and if I needed anything. Having a stoma can be a difficult thing to deal with but the level of care and service in my moment of need was above and beyond five-star. I thought that I should let you know as I have never had an 'issue' outside in the past two years and so was very anxious, but the way the staff looked after me was superb. *Many thanks, B Smith-Thomas*

Dear Colostomy UK,

I wonder if, like me, other readers have been turning out their cupboards during the lockdown?

In one I found my collection of Tidings magazines! Some of them were years old, from when the magazine only consisted of a few pages. What did come through was the support offered to old and new colostomates. YES - at one time it was thought that only colostomates would read the advice given for those with a stoma. How things have changed. Reading the latest edition, I am aware that all those with stomas, (colostomies, ileostomies and urostomies) benefit from the advice in Tidings.

I sat for some time reading the articles from "yesteryear" and as I read, I wondered what has happened to those who wrote their very personal stories? I can well remember reading my first issue of Tidings as I lay in bed recovering from the cancer operation that left me with a stoma.

It was the story of a woman and her trek around Nepal. I was so depressed I said to my husband (whinging - I think you would say) "AND I can't even trek round Sainsbury's."

Now of course I am fully in control of my stoma and I can wander around Sainsbury's to my heart's content.

I have to admit I have not undertaken any of the fantastic challenges that others have, but I continue to read stories of ostomates doing amazing things and I am delighted to read how well they have done. Looking back the stories always had a way of connecting with me - answering the many questions about stoma problems and supplies and making me feel not so alone. I always tell newcomers "Even though we have joined a club that we would rather not belong to, we have the most fantastic membership!" *Mrs G M K*

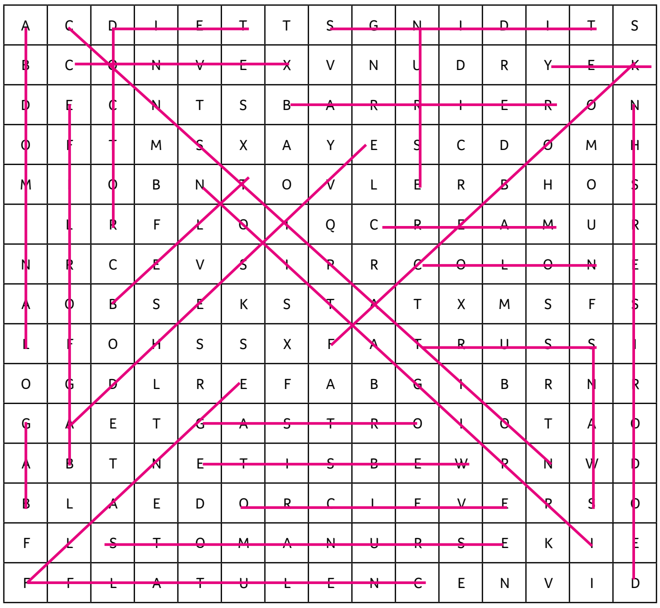
We look forward to hearing from you, our readers:

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

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

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

Solution



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News from Support Groups Across the UK

Support groups bring together people whose lives have been impacted by stoma surgery. The groups provide an opportunity for people to share personal experiences, feelings, coping strategies, and first-hand information about living with a stoma. If you are thinking of starting a support group, or running of an existing one, you can contact us for advice on 0118 939 1537 or info@colostomyUK.org.

Open Days

Stevenage Ostomistics Open Day:

Saturday 21st August 2021,
10.00am – 1.00pm

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

There will be two short talks from a specialist dietitian and a stoma care nurse about skin problems.

Contact: Judy Colston,
judycolston@btinternet.com
01438 354018

Shropshire B.O.T.S. (Bums on Tums) 2021 stoma open day:

Thursday 7th October 2021
10.30am – 3pm

Location: The Memorial Hall, Smithfield Street, Oswestry, SY11 2EG

12 Suppliers and Distributors will be exhibiting and promoting their products, including any new items and offering complimentary samples. Complimentary light refreshments will be provided and there will also be a raffle.

Contact: Irene Constable,
ireneconstable@phonecoop.coop
01691 238357

Click *here* to visit our open day page

Channel Islands

Guernsey

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

Jersey

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

England

Berkshire

E.B.O.C (East Berkshire Ostomy Club)
Jackie Dudley T: 01344 426 652

Reading Bowel Cancer Support Group
Ted Wingrove T: 0118 961 8297 or 07974 790 558

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

Bristol

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

Buckinghamshire

High Wycombe Stoma Support Group
T: 0800 318965

Milton Keynes Stoma Support Group (MKSSG)
Morag Harvey (Secretary)
E: mkssg.sec@gmail.com
T: 07843 768 386

You Are Not Alone Stoma Support Group - Chesham
Carla T: 07846 354 918
E: carlawright0502@gmail.com

Cambridgeshire

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

Cheshire

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

Stockport Support Group
Marion Caulfield
T: 0161 320 9400 / 0800 652 6667

Warrington Ostomy Support Group
Louise or Joan T: 01925 454 813

Cleveland

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

Co. Durham

Bishop Auckland Stoma Care Group
Mrs Maureen Davison T: 01388 818 267
E: rdavison816@gmail.com

Darlington Support Group
Margaret Clothier, T: 0191 333 2184

Durham Stoma Support Group
Lynn Ridley, T: 0191 333 2184

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Cornwall

Cornwall & Plymouth Bowel Cancer Support Group
The Secretary T: 01872 241 145
E: cbcsginfo@gmail.com
W: cornwall-bowel-cancer-support-group.co.uk

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

Cumbria

Grange Cancer Support Drop in
Marie O'Connor T: 01539 533 279

Stoma Support Groups in North Cumbria
Stoma Care Nurses T: 01228 814 179

Derbyshire

Diverted Local Stoma Support Group
Diana Manning T: 01283 541 311

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

Mercia Inside Out Stoma Support Group
Sally Chester T: 07500 441 442
Jackie T: 07919 002 612
Gary T: 07779 218 245

Devon

Devon IA
E: devon@iasupport.org

Mid Devon Ostomy Support Group
Janice E: janice234ford@gmail.com
T: 07923 975 051 or 01884 799 369

Plymouth & District Bowel Cancer Support Group
Secretary – Rita 0785 557 1840
E-Mail: admin@plmdistbcsg.com
Facebook: Plymouth Bowel Cancer

Dorset

Colostomy Urostomy Pouch Ileostomy of Dorset - CUPID (Bournemouth)
Beryl Andrews T: 01202 483 303

Colostomy Urostomy Pouch Ileostomy of Dorset - CUPID (Poole)
Jenny Pipe T: 01202 740 440

Colostomy, Urostomy, Pouch & Ileostomy of Dorset - CUPID (West Dorset)
Colin Clare T: 01305 853 238

Essex

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

Mid Essex Stoma Support Group
Paul Foulger T: 01245 224 374

N.E.S.S (North Essex Stoma Support)
Brian Waller T: 01206 540 449

Optimistic Ostomates
Angela Taylor T: 01702 385 510

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

STEPS - Stoma Essex Patients Support
T: 01268 451 937
E: stepsessex@gmail.com

Hampshire

Replummed stoma support group
W: replummed.me

Solent Ostomates Support Group (S.O.S.)
T: 07527 707 069
E: solentostomates@hotmail.co.uk

Southern Ostomy Group
Caroline or Karen
T: 07756 819 291 | E: southernostomygroup@hotmail.com

The Hampshire Ostomates Support Group
Nicki Beare T: 07771 558 458
E: Hampshireostomatesgroup@gmail.com

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

Wessex Urology Support Group
Mrs Jo Stacey T: 07910 786 978

Herefordshire

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

Ostofriends Stoma Support Group (Potters Bar)
E: ostofriends@gmail.com
T: 07596 748 376

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

Isle of Man

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

Isle of Wight

Optimistics
CNS's Sarah Capon & Sarah Varma
T: 01983 534 009

Kent

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

Dartford Ostomy Group Support (DOGS)
Tracey or John:
T: 07779 155 846 or
T: 07948 974 350 or
E: dogs-uk@hotmail.com

Dover Stoma Friends Group Support
Carolyn Fullager T: 01304 821132.

GOGS (Gravesend Ostomy Support Group)
Tracey T: 07779 155 846
or Helen T: 07710 780 958

M.O.G.S (Medway Ostomy Group Support)
Tracey T: 07779 155 846;
Helen T: 07710 780 958 or
E: mogs-uk@hotmail.co.uk

Maidstone Stoma Support Group
Judy/Kirsty T: 01622 224 305

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

SWANS Stoma Support Group Swanley
Heather T: 07711 445 312
E: heather601@virginmedia.com

Thanet Stoma Buddies Support Group
Kathy T: 01843 291 825

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

Lancashire

Kangaroo Klub, Blackpool Stoma Support Group
Blackpool Teaching Hospital
T: 01253 956 620 or E: crc-stomanurses@bfwhospitals.nhs.uk

North Manchester and Bury Stoma Support Group
Julie Meadows (SCN)
T: 0161 720 2815 or 07774 263 563

Oldham Stoma Support
June Wilde T: 0161 312 5538

Phoenix Bowel Cancer Support Group
Sandra Peet T: 01772 683 790
W: phoenixgroupbvh.com
E: sandrapeet7@aol.com

Leicestershire

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

Grantham Support Group
Bobbie/Rachel T: 01476 464 822

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London

Bowel & other Cancer Support Newham
T: 020 8553 5366

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

Newham Stoma support group
Contact Lauren King
T: 020 7055 5576

Rectangle - Colorectal Cancer Support Group
Regina Raymond
T: 020 7472 6299

South Woodford Support Group
Nurse Christina and Lisa
T: 020 8535 6563

Surrey & South London Bowel Cancer Support Group
Sue Berry T: 01737 553 134 or John Amos
T: 020 8668 0796

Time 2 Talk
Ifrah Mohamed T: 07463 838 718
E: mybodysauthor@gmail.com,
Viki Palmer T: 07894 276 986

Merseyside

Bowel Cancer and Stoma Support Group (BeCauSe Group)
T: 07948 120 955

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

St Helens Cancer Support Group
Denys Floyd T: 01744 884 097

Middlesex

Inside Out
Sarah Varma T: 0208 235 4110
Bob (Chairman) T: 020 8428 4242

Norfolk

James Paget Ostomy Support Group
Sandra Hutchings T: 01502 585 955

Kings Lynn Ostomy Friendship Support Group
T: 01553 775 698, 01553 674 962,
01553 768 271

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

Northamptonshire

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

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull T: 07714 479 320

Hexham Ostomy Group
Judith T: 07967 927 286

Northumberland Cancer Support
E: members@northumberlandcancersupportgroup.co.uk

Nottinghamshire

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

Nottingham QMC Stoma Support Group
Rosemary Brierley T: 0115 982 6691

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

Shropshire

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

Somerset

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

Staffordshire

County Stoma Group
Moira Hammond T: 07788 402 195
E: cm.hammond@ntlworld.com

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

Suffolk

East Suffolk Ostomy Group
Marion Fisher T: 01473 311 204

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

Surrey

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

Normandy Colostomy Support Group
Robin Young E: robin.young11@btinternet.com T: 01483 417 610
W: normandystomagroup.wordpress.com

Stoma Support Group
Robin Young T: 01428 723 255

Sussex

Brighton & District Support after Stomas (SAS)
Virginia Keefe T: 01273 723775

Chichester Stoma support Group
The Stoma Care Team
T: 01243 831 527

The Ostomy Friends Group
Jane Quigley T: 01323 417 400
ext 4552

West Sussex Princess Royal Stoma Support
Tina Walker T: 01444 441 881
ext 8318

Tyne and Wear

Gateshead Stoma Patient and Carer Support Group
Stoma Care Nurses T: 0191 445 3152

NHS Molineux Support Group
John Burchell T: 0191 265 1047

Royal Victoria Infirmary Support Group
Stoma care nurse specialist
T: 0191 282 4116

South Tyneside Hospital and Community Stoma Support Group
Jane Barnes, Amanda Logan:
stoma care nurses

Sunderland Support Group
Michele Downey T: 07704 949 30
E: micheledowney@outlook.com

Warwickshire

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

West Midlands

Birmingham, IA
Michael Jameson
T: 0121 355 2745 / 07842 555 070
W: birmingham.iasupport.org/events

Coventry Stoma Support
Martin T: 07947 385 643

Wiltshire

Swindon IA
w: swindon-ia.org.uk

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

Worcestershire

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

Yorkshire

Acorn Ostomy Support Group
T: 07580 693 155 (After 6:00pm)

Airedale Stoma Support
Sue Hall T: 01535 646 373

Barnsley Bottoms Up Stoma Support Group
Stoma Nurses T: 01226 432 528
or Celia Utley (Chairman)
T: 01226 284 262

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Behind You (Calderdale & Huddersfield Bowel Cancer Support Group)
Stoma Care Nurses T: 01484 355 062

Bottoms Up (for urology and colorectal cancer patients)
John Whelpton T: 07974 657 146 E: midyorks.bottomsup@gmail.com

Bradford Stoma Support Group
Lisa Hall T: 07552 276 747

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

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

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

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

Scarborough Stoma Support Group
Stoma Care Team T: 01723 342 388

Second Chance Ostomy Yorkshire
Jackie Butterworth, E: Secondchanceostomyyorkshire@gmail.com,
T: 07544882353

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

Northern Ireland

County Antrim

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

Colostomy UK Volunteers Northern Ireland
Chris Wright T: 07720 717 771

County Armagh

Craigavon Area Hospital
Claire Young/ Lynn Berry/ Tanya Garvie
T: 028 3756 1845 (Direct Line)

Daisy Hill Hospital Support Group
Bernie Trainor T: 028 3756 2932 (Direct Line)

County Down

North Down Stoma Support Group
Adrian Ewing T: 07850 741 511

Ulster Hospital
Hazel/Martina T: 028 9055 0498

Londonderry

Causeway Support Group
Mary Kane T: 028 7034 6264

Republic Of Ireland

County Mayo

Mayo Stoma Support
Marion Martyn T: +353 94 902 1733

Dublin

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

Scotland

Ayrshire

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

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

Fife

Fife Ostomy Support Group
Ishbel Barr T: 01592 772 200

Lanarkshire

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

Moray

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

Scottish Borders

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

West Lothian

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

Wales

Aberystwyth

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

Bridgend

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

Carmarthenshire

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

Conwy North Wales

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

Gwent

Blaenau Gwent Self Help
Celia McKelvie T: 01873 852 672 (after 6pm)

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

Mid Glamorgan

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

Pembrokeshire

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

Powys

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

Rhondda Cynon Taf

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

Swansea

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

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