

Tidings

AWARD-WINNING

Supporting & empowering ostomates

Our StomaAware Campaign Hits the Back of the Net

PAGE 26



PAGE 18

Leanne's story – an unexpected chapter!



PAGE 33

Andy Wakefield: I Wanted to Live to See My Daughter Grow

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Dear readers

By the time you read this the holiday season will be really revving up. Across the country people will be preparing to get away, with all the excitement and stress this brings. Then, all too soon, it will be over and we will find ourselves politely looking at friends' holiday snaps, while surreptitiously checking our watches and wondering how many more photos there are to get through!

Of course going away when you have a stoma can bring with it practical challenges as well as a few worries, regardless of whether you are snatching a few days in the UK or jetting off to foreign climes. This is why I asked our volunteers to contribute some of their holiday tips, which you can find on page 40.

In this edition we have four Real Lives stories, covering a whole range of issues. In Nav Johal's story we revisit reversals and use her experience to consider everything from preparing to talk to your healthcare team about the surgery to weighing up whether it is right for you. Just like Nav, Andy Wakefield was diagnosed with cancer in his late thirties. His treatment led to the formation of two stomas. He talks candidly about the impact this has had on aspects of his life and the importance of seeking help.

In Leanne Marsden's story we learn about the importance of being persistent when you know you aren't well. Our final story is an uplifting piece in which Amy Davidson recounts how having a stoma has allowed her to live the life she always wanted to, which has included trips to Africa volunteering with an NGO.

In Dear Nurse, Tammy Temple, who is a specialist stoma care nurse with Fittleworth Medical, takes a look at diet and gives some advice for readers who have a stoma and then go on to develop diabetes. This isn't something that we have covered before (at least to my knowledge!) and coincidentally is a topic that has cropped up recently in a number of calls to our Stoma Helpline. Another is pancaking. If you are affected, then head to pages 37 – 38 to read a whole range of tips we have compiled from ostomates who have engaged with us on social media about the issue. Finally, along with all the usual charity news we have a piece that's an ideal holiday read, particularly if you have an interest in history. On pages 14-16 we take a look at a self-help medical book from the eighteenth century and the suggestions its author makes for the treatment of 'inflammation of the intestines'.

Best wishes,

Richard

Richard Biddle
Editor, Writer & Researcher

PS: I'm also looking for a volunteer(s) who has writing skills and would be interested in writing for Tidings. You can find out more about what's involved in Colostomy UK News pp. 6-7.



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

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

How to contact us

Stoma helpline for:
Emotional support, experience-based advice and guidance from a volunteer.
0800 328 4257
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Adminline for:
Information packs, ID cards, RADAR keys, travel certificates and literature.
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If we're not in, just leave a message.
[Hello@ColostomyUK.org](mailto>Hello@ColostomyUK.org)

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Hello@ColostomyUK.org

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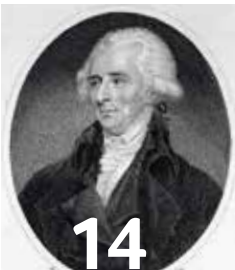
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Contents



Colostomy UK News

- 6** Colostomy UK: **News**
- 26** Colostomy UK: **Campaigns**
- 30** Colostomy UK: **Fundraising**
- 40** Colostomy UK: **Volunteers**

Real Lives

- 9** **Nav's Revolution** – By Richard Biddle
- 18** **Leanne's story – an unexpected chapter!** – By Alice Fitzgerald
- 23** **My Stoma has Finally Given Me Freedom and Now I Can Help Others** – By Amy Davidson
- 33** **Andy Wakefield: I Wanted to Live to See My Daughter Grow** – By Richard Biddle

Wellbeing

- 14** **A Look at Bowel Complaints and Their Treatment in the Eighteen Century** – By Richard Biddle
- 20** **Dear Nurse** – Mrs Tammy Temple
- 37** **Pancaking: Hints and Tips**

Support

- 44** **Your Letters and Emails**
- 46** **News from Support Groups Across the UK**

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



Colostomy UK news



Libby Herbert
CEO
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Active Ostomates in the Community

Support groups in Salisbury and Nottingham were amongst those to have benefited from our Active Ostomates Community sessions recently. The Wessex Stoma support group had a great chair Yoga session delivered by our instructor Suzanne, while ostomates in Nottingham showed their creative side in one of our Creative Minds art classes.

If you run a stoma support group and would like us to deliver a session to your members, please email getinvolved@ColostomyUK.org. We currently offer Art classes, Chair Yoga, and Pilates.

Wexham Park Hospital

We were thrilled to attend Wexham Park Hospital's recent open day.

Manning the Colostomy UK stand were Giovanni Cinque (Marketing Manager), Leanne Wood (Operations Manager) and Emily Crowley (Marketing & Social Media Executive). As newbies to the stoma world, it proved a great opportunity for Leanne and Emily to meet and speak with stoma patients and stoma care nurses. Both found it informative, learning first-hand about the challenges ostomates can face in day-to-day life. Indeed, Leanne commented afterwards that she found the whole experience humbling and at times emotional. It also helped our new team members understand better how, as a charity, Colostomy UK complements the work of healthcare professionals.



OPEN
DAY

MEETING WITH Kim Leadbeater MP

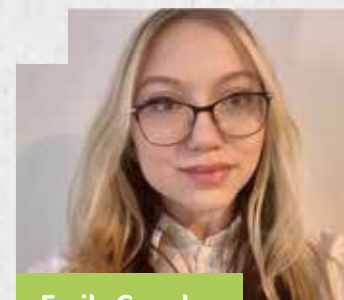
In April Libby and Giovanni met with Kim Leadbeater, the MP for Batley & Spen, to discuss how we might work together.



We first met with Kim last year when our Rugby League team played a curtain raiser to a Batley Bulldogs game, and her support played a big part in a successful day. The team are heading back to Batley on 4 June to play the British Asian Rugby Association as part of the Jo Cox Memorial celebrations. Kim is involved in the organisation of the day and with free entry a bumper crowd is expected.

Other areas of Kim's work as an MP that we are looking to support include the All Party Parliamentary Group for Loneliness and Connected Communities. It will be a good opportunity for us to explain to an MP the isolation many ostomates feel when, for example, there is inadequate toilet provision in public places.

We Welcome Three New Members to the Colostomy UK Team



Emily Crowley

Emily joined us in January 2023 as our new Marketing & Social Media Executive.

Her focus is on promoting Colostomy UK and the work we do across social media and our website. Emily describes herself as a creative individual with a passion for developing impactful visual media. This creativity is also reflected in her spare time, where she is a keen artist. Commenting on her first months

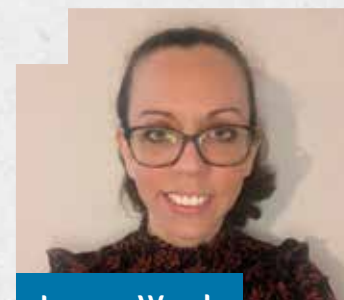
she said: "I have learnt so much about the stoma world already and how important it is to share stories and information with one another."

Alice joined us in March 2023 as our Fundraising & Communications Executive.

Having worked in marketing and communications for over a decade, she brings with her plenty of experience gained from stints in publishing, financial services, and tourism. A big part of Alice's role is supporting the fundraising efforts of all our wonderful supporters. Alice says she has been inspired by the personal journeys of so many ostomates and the vital support provided by the charity: "I am so pleased to have joined such a dedicated team and to be contributing to the valuable work of Colostomy UK." In her spare time, Alice likes to keep fit by playing Tennis.



Alice Fitzgerald



Leanne Wood

Leanne, our new Operations Manager also joined the team in March, having already worked in the charity sector for 15 years delivering a range of services to disabled adults.

Her focus is ensuring the day-to-day smooth running of the Colostomy UK office and the management of our support services. Although Leanne has only been with us a short time, she has been struck by the levels of

care and support we provide: "I have been astounded by what a difference such a small team of people can make in the stoma world and the amazing contribution of our volunteer community, and I look forward to being part of Colostomy UK's future." Outside of work, Leanne loves walking, swimming and cooking for her family.



Tidings Vacancy

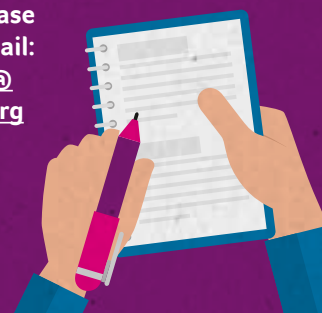
We are looking for an enthusiastic volunteer who can write articles for Tidings.

The role requires a time commitment of about ten hours per edition (four editions per annum) and will involve interviewing people, writing their stories and liaising with them throughout the editorial and publication process. Top-notch writing skills are a must, as is the ability to meet strict print deadlines.

As you will be talking to people about their experiences of stoma surgery and the impact it has had on aspects of their lives, you will need to be a mature and sensitive communicator.

All Colostomy UK volunteers are DBS checked and go through our volunteer training.

If you are interested and would like to find out more, then please drop me an email: richard.biddle@colostomyuk.org



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Active Ostomates sport and fitness after stoma surgery

Campaigns and Projects Flyer

Caring for a person with a stoma

Caring for a person with a stoma and dementia

Colonoscopy through a stoma

Fundraising Pack

Healthy Eating

Helpline Cards

How will a stoma affect me?

Irrigation Booklet

Irrigation DVD (nurses)

Irrigation DVD (patients)

Legacy Flyer

Living with a stoma

One to one

Ovarian Cancer and stomas

Pain and discomfort

Parastomal hernias

Rectal discharge

'Sam has a stoma' colouring book

Stoma friendly toilet guideline and stickers

Stoma reversal

Tidings magazine

Travel advice

Travel certificate

Tri-Charity leaflet

Welcome pack

Nav's Revolution

BY RICHARD BIDDLE

Not everyone can have a reversal, but with 'Stoma Reversal' continuing to be one of Colostomy UK's most popular booklets and with calls to our stoma helpline about the surgery being so frequent, we know that it's a topic of importance to many people. If you are about to discuss the possibility of a reversal with your surgeon, are contemplating whether to go ahead with the surgery, or perhaps even have the date booked, then what follows is a must read. In the space of just over three years Navneet (Nav) Johal has gone full circle. She had an ileostomy in March 2019, a reversal in May 2021, and then a colostomy in August 2022.

Nav, who is a detective with the Metropolitan Police, was diagnosed with bowel cancer in February 2019. Her symptoms started in the summer before with intermittent bleeding when she went to the toilet. At first she wasn't worried, but when the bleeding got worse and she found herself needing the toilet more often, she made (with encouragement from her twin sister) a doctor's appointment. The doctor organised blood tests, but didn't seem overly concerned, possibly because Nav was only 38 years old, and so didn't fit the profile for bowel cancer.

The results came back all ok, but the doctor Nav saw to discuss them wasn't happy putting her symptoms down to



IBS and so booked her for a non-urgent colonoscopy. By the time Nav had this in January 2019 she had started to lose weight and was feeling ill. The procedure revealed a 10cm tumour in her lower rectum, which biopsies later confirmed was cancer. Nav had stoma surgery just over a month later and learned shortly afterwards that a reversal was possible.



When I met with Nav we talked at length about her expectations from the reversal, how she prepared for it, and the discussions she had with her healthcare team both before and after. In a nutshell, Nav hoped that the reversal would mark the end of a difficult chapter in her life. In her own words she wanted 'normal Nav' back: the Nav who could eat what she wanted, go out when she wanted, exercise and play sports when she wanted, and didn't have a stoma to remind her each day that she had cancer. She did not, however, proceed with the surgery with a cast iron guarantee that this outcome could or would be achieved.



On the day Nav left hospital following her ileostomy surgery she asked when she could have a reversal. Such eagerness is not uncommon. Nor is it unusual for people to see reversal surgery as drawing a line in the sand, as Nav did to begin with. While this is understandable, it can make things difficult in the long term, if the surgery fails to meet expectations. Nav remembers this conversation well as it was the first time that it really sank in that after a reversal, function may not return fully to normal; she was too much in shock at the news to do much more than register the possibility.

Nav's reversal was initially scheduled for April 2020. Prior to it being booked she spoke to her stoma care nurse and also had more in-depth appointments with her consultant, where he discussed her options and also re-iterated that a complete return to normal function may not be likely. He told Nav that further surgery of some sort was required as, with an ileostomy, it wasn't possible to carry out a full surveillance of her rectal area (routine checks for cancer). Her options were to have a colostomy or, alternatively, a reversal and then if this didn't work a colostomy.

Nav admits that this wasn't news she wanted to hear and, although it didn't change things materially, she wished she had been told earlier that staying with an ileostomy was never really an option. It made her begin to wonder about having a reversal and whether it was worth going for this option if the chances of failure were high, as it would mean putting herself through yet more surgery afterwards. In other words, would she be better to go straight from ileostomy to colostomy?

When she voiced these concerns, her consultant explained that the reversal wasn't a huge operation for her, and this was the route he recommended. Then, if it ultimately didn't give her the function she needed for her lifestyle, the fallback position was a colostomy. As Nav's experience shows, the decision to have a reversal is not necessarily as straight-forward as one would think. Many factors have to be considered. This is why it is so important to prepare ahead of time for discussions with your healthcare team. Taking everything into consideration Nav decided to go ahead and, even

though things didn't work out for her in the end, she still believes that trying a reversal first was the correct course of action for her. In her view, if she hadn't then there would always have been that doubt in her mind.

In the end Nav's reversal was delayed for over a year because of Covid and didn't happen until May 2021. Understandably this led to uncertainty and caused anxiety as she waited for the postman to deliver 'the letter'. As we recently reported, this was something experienced by other ostomates* during the pandemic. But it gave her plenty of time to prepare physically and mentally. For Nav, this meant working out. She was keen to get as fit as she could, the thinking being that this would aid her recovery. The physical exercise she did gave her focus, which she believes helped prepare her mentally as well. She was also determined to put on some weight, remembering how much she lost with her stoma surgery. Eating well was a part of her preparation she really enjoyed!



Nav was in hospital for two weeks after her reversal, primarily because her bowel took time to wake up (ileus). Although we don't have the space to cover it here, aspects of her post-op hospital experience were similar to those of John Hunter whose story 'My Reverse Operation' we featured in Summer 2022 edition of Tidings. Nav had generally good control from the start. This had been her overriding concern and so she arrived home sore but feeling positive that good function would be restored over time.

Nav persevered for over six months before concluding that the reversal had not been successful. Although her function improved, it didn't improve enough. Going to the toilet was a constant issue. She felt that she needed to go, but often couldn't. Rectal dilations were tried, as were daily enemas (for three months) and, although these helped, they were not a long-term solution. In addition, despite re-introducing foods very slowly to her diet, eating continued to be a problem. Nav found that she was constantly hungry and constantly in pain which,



she says, made her moody and difficult. She tried fasting to give her bowel a rest and this worked to a point, in that eating little for a couple of days was followed by a 'good bowel day'. But, again, this wasn't commensurate with an active lifestyle. Her consultant explained that further improvements could be expected over the coming years, but Nav decided that the percentage improvement he anticipated was not enough to make life tolerable or allow her to do the things she loved, such as going out with friends and family and playing football.

The decision to have a colostomy came after much deliberation and discussion with her consultant. Nav was obviously disappointed but does not regret having tried a reversal first. Once the decision to have a colostomy was made, she felt relief. By this point, she had exhausted all other avenues and knew that she needed to go back to a stoma in order to have the life she wanted. Her stoma nurse also said a colostomy would be easier to manage than an ileostomy. This proved to be the case. When we spoke last autumn, she was back at work on light duties and hoping to be fully operational again soon. This had not been possible in the post-reversal period. She was also running and playing 5-a-side football again, although no-one was allowed to tackle her too hard. She could also eat pretty much what she liked. Her output levels were consistent, and her bowel had already settled enough for her to confidently use a stoma plug when running or at the gym for a couple of hours.

In deciding whether to have a reversal, Nav thinks the fundamental thing to consider is your lifestyle (or what you would like it to be) and then asking the question: If I have a reversal, what are the chances of me being able to have this lifestyle? Regardless of the reason why you might have had your stoma in the first place, this is a helpful way to approach discussions with your consultant. Nav also stressed the importance of asking about possible complications, along with talking through and being clear about what your options are (as she did) should the desired level of function not be achieved. Although such advice might seem readily apparent, at Colostomy UK, we recommend going as far as writing down all your concerns and questions before a consultation. This way there is less chance of forgetting something, which is all too easy when you are talking with a doctor!



'The Psychological impact of Delays to Reversal Surgery', by Kate Andrews (Summer 2022: Tidings)





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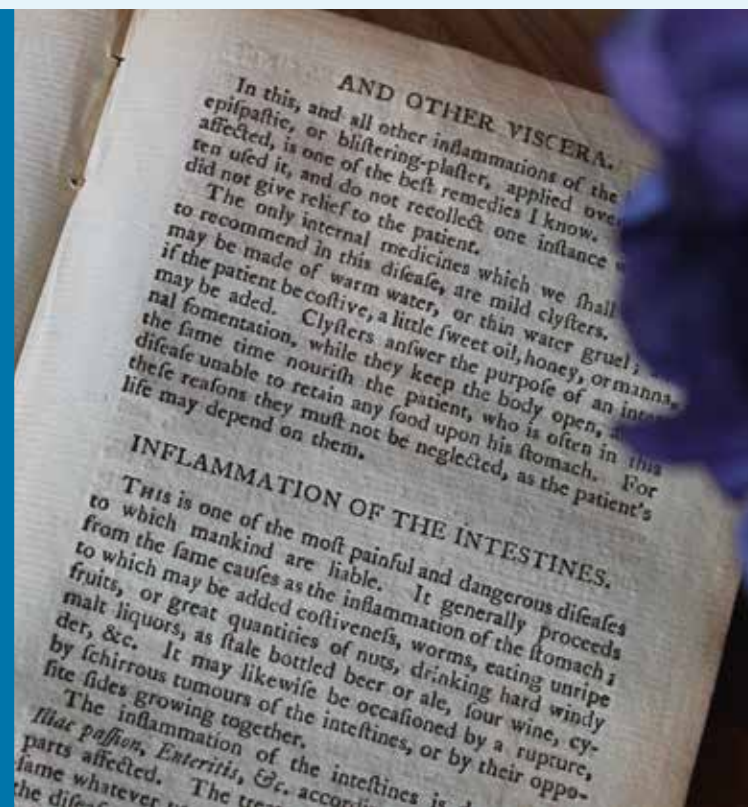
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A Look at Bowel Complaints and Their Treatment in the Eighteen Century

BY RICHARD BIDDLE



Who remembers *Doctors Answers*? For those that don't (or claim to be too young...) *Doctors Answers* was a weekly magazine in the early 1980s. Priced at 65p, it ran for over two years, during which time those dedicated enough to buy all 112 issues ended up with their own A – Z encyclopaedia of family health. Richly illustrated, it covered everything from anatomy and injuries to the diagnosis, treatment, and prevention of illness. Rather than being anything new, it was just another publication to add to the many others about family health around at the time.

Indeed, self-help medical books have a long history. John Wesley's *Primitive Physick*, was one of the first. It hit the shelves in 1747. Possibly the most famous is *Domestic Medicine* by William Buchan. This appeared in 1769 and went through multiple editions. It was so popular it was claimed that every cottage in Scotland had a copy, along with their copy of the Bible.

Domestic Medicine was a volume of nearly 800 pages which aimed to bring medicine to the masses, empowering people to prevent and cure diseases 'by Regimen and Simple Medicines'. It is a book I have studied over the years and used frequently when I taught the history of medicine to undergraduates. I'm also lucky enough to own a copy of the 1803 edition. Like the earlier editions it includes a section on 'Inflammation

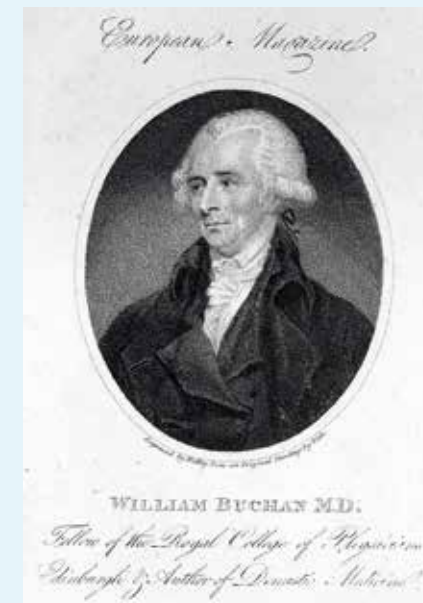
of the Intestines'. Although this was almost certainly written before the first recorded stoma surgery in 1783, I thought you might find it interesting to know a little more about how diseases of the bowel were understood, diagnosed and treated in the eighteenth and early nineteenth century.

William Buchan was born in 1729 in Ancrum, Scotland to a well-to-do family. He attended grammar school and then went to Edinburgh University where he studied medicine and qualified as a physician in 1758. In a career spanning 47 years, he practised in Yorkshire, Edinburgh and London and for a period was a physician at the Foundling Hospital in Ackworth. He was also a Fellow of the Royal College of Physicians, Edinburgh.

Buchan and his contemporaries understood the body in a way that is completely alien to us today. They had little appreciation of how disease can affect specific organs or parts of the body. Instead, they worked within what is called a Galenic framework. Put simply, this considered the body to be comprised of four humours or fluids (Blood, Black Bile, Yellow Bile and Phlegm). When these humours were in balance a person was healthy, but when they went out of balance (e.g. too much or too little of one or more humours) they became ill.

The causes of imbalance were thought to include everything from eating too much or the wrong things, to changes in the environment, or, if you were a woman, then reading too many books or watching plays that overly excited the passions.

The physician's job was to restore this balance. After listening to the patient's account of what was wrong, taking their pulse and examining things like their urine, physicians came up with a treatment plan or 'regimen'. This contained advice about diet and exercise and might include a prescription for medicine too. The latter focused on helping the body's natural ways of maintaining balance by ridding itself of excess or corrupt humours. Hence drugs that caused patients to vomit, sweat or open their bowels were common. Getting an extreme reaction was regarded as evidence that the medicine was working (something we still think today!). Letting blood featured prominently too, as this was seen as a great way of removing excess humours.



Credit: The Wellcome Trust
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Hopefully I haven't bored you, but some knowledge of the medical world Buchan inhabited is necessary to make sense of what he says about inflammation of the intestines and the weird and wonderful treatments he suggests. From a quick read it is evident that while he knew different parts of the bowel could be affected, he considered the problem to be all one disease or illness. Hence, terms we are familiar with, such as diverticulitis or Crohn's, don't appear in *Domestic Medicine*, although from his mention of 'ruptures', 'scirrhus tumours' and the 'opposite sides [of intestines] growing together' it seems clear that his patients suffered from what we now know to be specific conditions. Given how Buchan understood the body (four humours) and the way different bowel

complaints often manifest themselves in similar symptoms, it is not really surprising that he thought in terms of a single, general disease or illness.

Buchan identified a multitude of causes. These included: 'cold liquor drank while the body is warm', 'corrosive poisons, and such like', 'hard or indigestible substances taken into the stomach, as bones, the stones of fruits etc.', 'costiveness' (constipation), 'worms', 'eating unripe fruit, or great quantities of nuts', 'drinking hard windy malt liquors... stale bottled beer or ale, cyder etc.' Many of these causes speak directly to Galenic understandings of the body. It was thought that too much unripe fruit for example, might result in the body producing an excess of one or more humours, causing an imbalance to occur. Likewise, it was believed that the ingestion of a stone or a bone might interfere with going to the toilet, which was one of the body's natural ways of getting rid of excess humours and thus maintaining balance.



Many of the symptoms Buchan described will be familiar. He says that inflammation of the intestines was accompanied by pain (often acute) situated low down in the abdomen. Patients were also prone to vomiting (sometimes violently) and more rarely to 'even excrements... discharged by the mouth'. Other symptoms included a 'low fluttering pulse', 'pale countenance', 'clammy sweats' and 'black foetid stools' coupled with 'a small intermittent pulse'.

Buchan offered a gloomy prognosis for sufferers. In his experience, inflammation of the intestines was 'one of the most painful and dangerous diseases to which mankind are liable'. His narrative becomes increasingly pessimistic as he tracks the stages through which he thought patients passed when treatments failed. He tells us that: 'While the pain shifts, and the vomiting only returns at certain intervals, and while clysters (enema) pass downwards, there is ground for hope' but, as the disease progressed a 'total cessation of pain' was a sign that 'mortification [had] already begun, and of approaching death'.

It isn't particularly surprising that Buchan viewed inflammation of the intestines in this way, given the limited (and largely ineffective) treatment options open to him.

As we know, modern medicines are capable of managing bowel diseases for long periods, but surgery (stoma surgery included) is sometimes necessary. This form of intervention was not available to Buchan. What's more, if you believe that health is all about balancing fluids in the body and have no concept of the localisation of disease, then the idea of opening someone up and quite literally 'cutting out' the cause, wouldn't cross your mind.

While a sufferer was being treated Buchan stated a particular 'regimen' should be followed. The patient he advised: 'must be kept quiet, avoiding cold, and all violent passions of the mind. His food ought to be very light, and given in small quantities; his drink weak and diluting; as clear whey, barley-water, and such like'.

As you can see, I wasn't joking earlier when I said a Galenic physician saw too much excitement as being a cause of imbalance and thus disease!

Despite having an incorrect understanding of bowel disease(s) some of Buchan's treatments are still relevant today, such as using diet to encourage going to the toilet. Buchan suggested starting with 'barley-water or thin gruel with salt, and softened with sweet oil or fresh butter'. We see diet as a way to tackle constipation or a blockage (see Dear Nurse, Tidings Spring 2021). Buchan saw it as helping the body to rid itself of excess or bad humours. He also recommended 'fomentations' along with regularly bathing the patient's feet and legs in warm water and applying bladders of warm water to their belly, thinking this would help restore balance to those with cold sweats. For him, this was a treatment. For us, a hot water bottle on your

tummy doesn't tackle the cause of the problem but is a way to alleviate pain.

Beyond the above, Buchan's treatments either did no good or were harmful, to the point where the sufferings of patients with long-term bowel conditions doesn't bear thinking about. He declared that 'Bleeding' patients was of the greatest importance. If you remember, bloodletting was regarded as vital in removing excess or bad humours. He contended that bleeding should take place as often as 'the strength of the patient permitted'. He also recommended that strong laxatives and purgatives were used along with: '... twenty-five drops of laudanum... to appease irritation, and prevent vomiting'. In desperate cases he advised giving quick-silver (mercury), a single dosage of which should not exceed 'one pound'. As you will recall I mentioned earlier that medicine was thought to be working if it led to an extreme reaction...



Other treatments were downright bizarre. He explained that: 'It has sometimes happened, after all other means of procuring a stool had been tried to no purpose, that this was brought about by immersing the patient's lower extremities in cold water, or by making him walk upon a wet pavement, and dashing his legs and thighs with cold water.' This method he argued 'at least merits a trial', when others have failed.

Please let me know if you have enjoyed this little journey into the past. In the meantime, my advice is to avoid stoma care nurses carrying buckets of cold water!

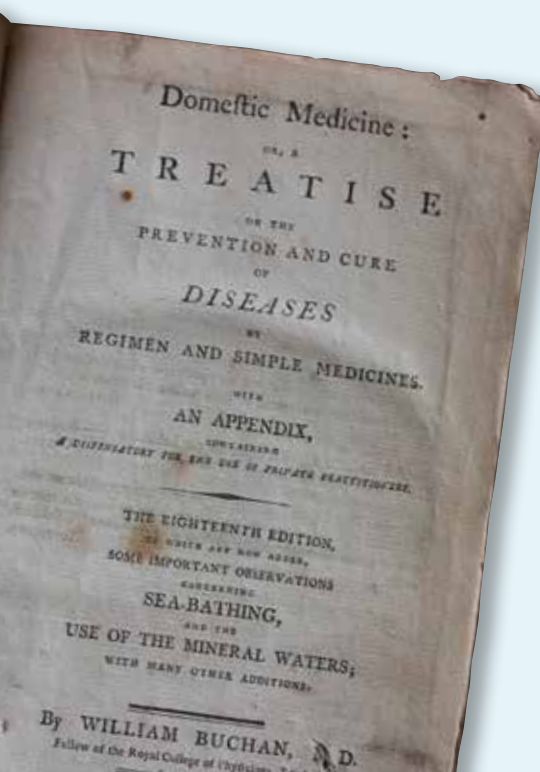
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Leanne's story – an unexpected chapter!

BY ALICE FITZGERALD

When Leanne Marsden went to hospital to have her first child at the age of 25, what started out as a familiar story of childbirth and the ensuing joy of becoming a new mum, soon changed into a very different narrative, leading Leanne to need urgent, lifesaving stoma surgery and opening a new and unexpected chapter in her life; one in which she learned that sometimes you have to be persistent asking for help when you know you aren't well.

Leanne was at her parent's house when her waters broke five weeks early. Like many expectant mums her excitement was tinged with nerves at the prospect of having a baby and becoming a first-time parent. As someone who had previously worked in a healthcare setting, going to hospital was less daunting for Leanne than for most. This changed quickly though when after being admitted on to the labour ward an early examination revealed Leanne had a lump on her cervix. Doctors rushed to undertake a biopsy fearing cervical cancer and immediately booked her in for an emergency C-section, the very next day.

Without knowing the results of the biopsy, Leanne was given an epidural in readiness for her C-section but plans suddenly changed as it appeared she was further along in her labour than had previously been anticipated. After a mere eleven minutes, Leanne gave birth to a healthy baby boy and to her great relief was subsequently given the 'all clear' from her biopsy.



However, just before her son turned one, Leanne noticed that her stomach was extremely bloated. Like many new mums, a change in body shape is not unusual when stomach muscles have been stretched during pregnancy, but Leanne was certain it was unconnected to childbirth. To try to alleviate her symptoms, she decided to change her diet, cutting out fizzy drinks and altering her contraception pills but, despite her best efforts, these changes seemed to make little difference. Although Leanne had suffered from endometriosis and its symptoms previously in her life, (a condition which causes tissue to grow outside of the uterus causing pelvic pain – see Kathryn's Story Tidings winter 2022 edition) it had never caused this kind of bloating, so she insisted the matter be investigated by her doctor.

Leanne was referred for a Laparoscopy, a procedure that uses a small camera to see inside the stomach under general anaesthetic. Unsurprisingly, the results revealed Leanne had stage 4 endometriosis, the most severe form of this condition. After the laparoscopy Leanne healed quickly, but despite the diagnosis, the pain and heaviness she was experiencing in her stomach continued, leading her to suffer several panic attacks, which only exacerbated the situation. In desperation, Leanne contacted the surgeon who had undertaken her laparoscopy and was reassured that such symptoms were not uncommon after a surgical procedure and would subside in time.

However, despite this reassurance, Leanne's pain continued to worsen. She tried to self-manage the situation for several years until last year when her symptoms became so severe her brother rushed her to Accident & Emergency. The consultant she saw suggested some of her pain might be psychosomatic. Somewhat demoralised, but with the symptoms easing, Leanne discharged herself from hospital. But it was only a matter of weeks before she experienced a resurgence of acute stomach pain to an intolerable level. Her brother immediately dialled the emergency

services, and an ambulance duly came. Leanne was given gas and air to help reduce the severity of her symptoms and taken to hospital. At this point she could barely sit and every moment she spent waiting to be seen felt like an ordeal. Thankfully, a bed became available, and she was admitted onto a ward for further tests.

The following morning was Christmas Eve, a time for celebrating with family and friends but Leanne remembers little of the day's events, other than being told by a gynaecologist that she would need emergency stoma surgery.

So, Leanne woke up on Christmas day morning 2022, with a stoma and stunned at the sudden turn of events. She later learned that her bowels had almost ruptured and had the situation been left much longer the consequences could have been dire.

Despite her surgery, the doctors weren't sure of the root cause of Leanne's bowel problem, so she continued to undergo a battery of tests, including an MRI scan. There were conversations around Crohn's disease instead of Endometriosis but at the time her tests seem to raise more questions than answers.

With her son now six years old Leanne is due an operation to reverse her stoma. The surgery will be significant, involving a partial removal of her bowel, along with her fallopian tube and an ovary. Leanne is looking forward to her reversal because in many ways, if successful, it will simplify things. But having a stoma didn't deter her from being active in all aspects of her life: from work to socialising, or in her choice of clothes. In fact, she credits her

stoma for saving her life. Rather than life limiting it has been life enhancing, because it freed her from pain and allowed her to concentrate on being a mum! She also knows that without it, she may not have been around to share her story; a situation she is all too aware of having lost her father a few years ago and bearing witness to her mum's heroic battle with cancer.

Fortunately, Leanne has been supported throughout her stoma journey by her partner, wider family and friends, who have all drawn closer together by this shared experience. But perhaps the most significant lesson Leanne has learnt during this episode in her life, is to be persistent if you feel something isn't right with your health because that persistence could be lifesaving.





dear nurse



Mrs Tammy Temple
Specialist Stoma Nurse
Fittleworth Medical Ltd

I have a stoma, now I have diabetes – what can I eat?

I have been a specialist stoma nurse for three years, and prior to this I worked in general practice for six years. My role in general practice was supporting patients with long term conditions, mainly diabetes.

In my clinical setting I often review established ostomates who are developing other health complications. One of the most common is type 2 diabetes, which is a condition that is on the increase in the UK.

I am often asked about the best ways to manage the two diets as the advice can be contradictory.

I have just been diagnosed with diabetes – what can I eat?

The general dietary advice for someone with a stoma is the same as a person without, namely a healthy balanced diet.

After a diagnosis of diabetes, this general advice doesn't change. Specialist diabetes nurses often recommend a diet containing things high in fibre, such as wholemeal breads and cereals, fresh fruit and products high in protein such as chicken, cheese and eggs. As readers will know while these food products are often suitable for ostomates, some of them can cause problems. For example, too much fibre can cause watery output and some fruits can cause blockages due to skin or seeds. This can be confusing for people about what they should and shouldn't eat.

Historically, diabetes guidance focused on sugars that were eaten, however current guidance and research now focuses on carbohydrates. A low carbohydrate diet can improve diabetes and also promote weight loss, which will also improve diabetic control.

Aim for 130g of carbs a day or less



The aim of maintaining a low carbohydrate plan is eating 130 grams of carbohydrates a day or less. This level of carbohydrates can improve diabetic control and focusing on carbohydrates enables an ostomate to make suitable switches for both stoma and diabetes management.

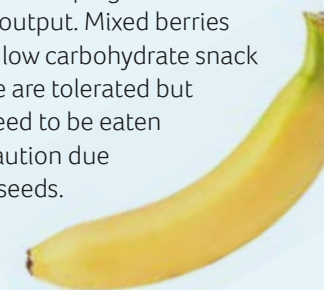
Bread is a good example of this. One standard medium slice of wholemeal bread has approximately 14 grams of carbohydrates, while white bread has approximately 13 grams. From a diabetes management plan either would be suitable, but wholemeal products are often suggested with diabetes management as they have a greater effect on the glycaemic index.

Glycaemic index is the rate that carbohydrates are broken down in the body. The higher the GI index the quicker these are broken down causing a rise in blood glucose levels. Jelly sweets will have a high GI index while porridge oats will have a low GI index and having an understanding of this can help improve diabetic management.

White starchy products however can thicken the output of a stoma and therefore may be more suitable for an ostomate.

What fruit can I eat?

Although fruits have natural sugars and may need to be eaten in moderation with diabetes, they offer a good solution for a snack that will keep you fuller for longer. Some fruits offer more fibre than others, which may cause wind and produce a more frequent output. While this may result in more frequent pouch changes, fruit you can tolerate as an ostomate should be incorporated as part of a healthy balanced diet. Bananas are a good example of suiting both eating plans as they are low in carbohydrates while also helping to thicken a looser output. Mixed berries offer a low carbohydrate snack if these are tolerated but may need to be eaten with caution due to the seeds.



Can I have protein with my meals?

Yes you can. Fish, poultry, lean meats and eggs all have health benefits both for an ostomate and someone living with diabetes. Proteins are necessary for the repair and growth of the body's tissues. Other sources of proteins are whole nuts (e.g. cashew nuts and almonds), peas, beans and lentils. While these have the health benefits of being high in protein and low in carbohydrates these can lead to constipation with a stoma and may need to be eaten in small amounts. Quorn and tofu products are both low in carbohydrates and high in protein.



Foods to reduce

Some ostomates may have foods such as jelly babies and marshmallows to thicken their output. While these are an effective way to thicken output,



both are high in carbohydrates. Four large marshmallows for example, have 25 grams of carbohydrates.

Pasta, rice, white bread and bananas are alternatives that can be eaten to help thicken output. Comparing the carbohydrate content of these products demonstrates what an effective switch this would be to both thicken output and improve diabetic control. Two slices of medium white bread have around 30 grams of carbohydrates and a medium sized banana approximately 17 grams, demonstrating the effectiveness of such switches. Both can help to thicken the output but with the lower carbohydrate value improve diabetic control. Both would also be a more substantial snack, reducing the need for further snacking (such as another four marshmallows!).



Summary

Having a healthy balanced diet is the advice for all ostomates and this does not change when managing diabetes. Sometimes diet is trial and error, especially if trying new foods. Keeping a food diary when introducing new foods, while adding new foods one at a time, can help identify those that work and those that cause problems such as watery output or constipation.

For further dietary advice and support speak to your stoma nurse or diabetes team.



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My Stoma has Finally Given Me Freedom and Now I Can Help Others

BY AMY DAVIDSON
amydavidson123@gmail.com

My bowel problems first became apparent when I was around four months old. Until then, like all other young babies, I was only consuming breast or formula milk. From four months, my mum started feeding me baby rice and pureed fruits and vegetables alongside milk. This was when it became obvious that something was wrong. I had chronic constipation. I couldn't pass stools properly, and when I did it was only around three times per week, and I was in a lot of pain.

I was tested for every condition the doctors could think of, I was referred from professional to professional, and undertook a combination of behavioural, medical and nutritional treatments. Nothing was successful. I was diagnosed with Idiopathic Chronic Constipation, which means that the cause of the constipation was unknown.



By pre-school age, I was taking multiple oral laxatives, as well as enemas and suppositories, none of which were enough to keep my bowels clear of faeces. On three occasions between the ages of five and eight, I had to be put under general anaesthetic to have faeces removed from my rectum. I was even given Botox into the anal muscles to try and support my bowel to empty more effectively. Nothing seemed to stabilise my situation.

As I reached my later childhood and early teenage years and I became more of 'my own person', I was managing my situation myself. There was less and less intervention from medical professionals and my parents, and often no medication. Although I regularly became very unwell and often had to visit A&E, the problem was always swept under the rug very quickly, and I would just have to go back to dealing with it by myself. At 14 years old, I got my first job. I did a paper round seven mornings a week until I left college at 18. I got £25 a week and would often spend my money in Holland and Barrett buying different probiotics and supplements which were meant to improve digestive health.

Looking back now, I don't know how I did it. I was attempting to manage being a normal young person, going to school and sitting exams, maintaining friendships, planning for my future, and working part-time, alongside absolutely debilitating

symptoms. My body was in a very unhealthy cycle for several years. I would go between four and eight weeks without opening my bowels. And for one to two weeks following this I would have constant faecal overflow. This is where watery stools leak out around the hard blockage of stool which cannot exit the rectum, giving the appearance of diarrhoea. At the same time, I was dealing with sickness, light-headedness, abdominal pain, major bloating that made me look like I was pregnant, and feeling constantly exhausted.

In 2016, when I was 18 years old and I could manage all of my healthcare without a guardian, I went back to my GP. I was started back on laxatives and began once again to get my problem investigated. I had blood tests to check for coeliac disease. I was also referred to Gastroenterology who sent me for chest and abdominal x-rays, an ultrasound scan, gastroscopy, and colonoscopy. I became more and more unwell and was admitted to hospital for a short period of time. I was dosed up with around ten different kinds of laxatives, none of which helped, and I was referred to a specialist bowel hospital. By this time, I had also visited my GP again for depression. I was given antidepressants and had several rounds of Cognitive Behavioural Therapy, none of which helped. I was miserable and very unwell. It got to the point where I began to save up a multitude of different types of antidepressants, in case I ever felt everything was too much.

I waited six months for my only appointment with the specialist bowel hospital. I saw a registrar who completely undermined what I was going through and suggested that I had IBS and that I should get used to it. Disheartened by this outcome, in early 2018 my family used the little disposable income they had to pay for me to be seen privately by a colorectal surgeon. He had treated patients with my symptoms before and wanted to run a colonic transit study which assesses the functioning of the digestive system.

This investigation showed that my digestion was completely fine until it reached the large intestine. After that it almost completely stopped due to slow movement, multiple hard masses of stool stuck in my bowel, and my bowel being swollen after years of damage. The surgeon referred me back to his NHS patient waiting list for a subtotal colectomy. The plan was to remove three-quarters of my large intestine in the hope that this would allow the smaller portion of remaining bowel to push faeces through more efficiently.

Shortly after having the subtotal colectomy, in October 2018, it quickly became clear that the surgery hadn't been enough to improve my bowel function. I went straight back to being very unwell. I had severe constipation, and my bowel still didn't work properly without the assistance of multiple types of laxatives per day. After months of trialling medications I had taken years before and two more transit studies, I sat opposite my surgeon in his office. He told me that he was willing to cut more of my bowel out to try and improve my situation. But he also asked me something no doctor had asked me before: what did I want him to do?

By this time, I had done a lot of my own research and was almost certain I knew the procedure that would give me the best quality of life. I told him I wanted an ileostomy. Two months later, in November 2019, he performed the surgery to create my loop ileostomy.



After the surgery I very quickly realised I had made the right choice. My stoma started working very quickly, and almost immediately I felt so much better.

In 2020, my surgeon had carried out tests to ensure that my small intestine was functioning effectively and was unlikely to cause any future complications. Then, in October, I had my third and final major surgery to remove the remaining quarter of my large bowel, and to make my loop ileostomy into a permanent one. Leaving the hospital after my last surgery felt like a dream; I had never imagined feeling so well, and I was beyond happy and grateful.

And now? My life is everything I could have ever dreamed it would be, and more. I have been a carer for the elderly since I was 18 years old. Even though I have now officially left this job to become an NHS healthcare assistant in a specialist bladder and bowel care clinic, I still go back to the care home to work night shifts when I can. I have an amazing and supportive family and lots of wonderful friends, all of whom mean the world to me. I am well enough to travel on volunteer trips to Africa with various charities, which is something I have been passionate about since I was really little.

With my background in healthcare and being an ostomate, I have naturally been curious about what life looks like when you have an ostomy in a place where healthcare is limited and medical supplies are scarce and expensive. In September 2022, I went to Zambia with a charity called Footprints Foundation for Children in Zambia. After my trip, I started looking into stoma care in Zambia and found an NGO called 'Stoma Care Support Zambia' based in Lusaka, the capital city of Zambia. Its aim is to provide free ostomy bags and supplies to people living with an ostomy, helping them to live normal manageable lives. It also trains medical professionals on how to provide stoma care.

Through meeting virtually with founders of the NGO, I found out that a lot of people living with ostomies in Zambia have never seen or used a stoma bag before, and use pieces of cloth, clothing, or cut fabric from mattresses to put over their stoma. Others use bottles or cans that they attach to their abdomen with tape. Stoma Care Support Zambia has so far managed to make connections with 400 ostomates in Zambia and given out over 50,000 stoma bags to individuals and hospitals since June 2019. To help out, I'm starting a collection of ostomy bags and supplies to send out to Zambia, so that they can be given out for free to those who need them most.



I hear a lot of people talk about how their stomas gave them their lives back, but as someone who has had their condition since they were a baby, I had never experienced life without being unwell. I think that my curse and my saving grace throughout my life was that my body adapted around my illness as I got older and therefore, I was normally able to have some sort of functionality. Essentially what my stoma gave me was the freedom I had never had. And more importantly, the ability to use that freedom as a way to help others.



My advice to any young person growing up with a severe undiagnosed bowel condition would be to remember that you are the expert of your body and deserve to be taken seriously. Don't be afraid to be a bit of a pain sometimes to make your voice heard. It took me years to realise that I had a say in the treatment I receive. The only reason I have a stoma is because I told my surgeon I believed that would be the best option for me to have a good quality of life.





campaigns



Giovanni Cinque
Marketing & Campaigns Manager
GetInvolved@ColostomyUK.org



Stoma Friendly Toilets UPDATE

A big thank you to everyone who has asked for a Stoma Aware pack following our request in the last edition for people to help at a local level in our campaign for more stoma-friendly toilets.

The pack contains everything you need to approach councils, businesses, and organisations in your area, and encourage them to make their facilities stoma friendly. It includes a letter you can print off and send, our stoma-friendly toilet guidelines and a Stoma Aware poster.



Packs can be downloaded from our website www.ColostomyUK.org/campaigns or if you'd like us to send you hard copies email GetInvolved@ColostomyUK.org

Since the last edition we've had some great successes and can report that the following have upgraded their facilities: Rochdale Leisure Centre, Middleton Arena, Heywood Sports Village, Littleborough Sports Centre, The Braken Trust, The University of Northampton, Arena Business Centre Winnersh, The LGBT Foundation, and South Lanarkshire College.

Through our partnership with Level Playing Field, we're also delighted to be able to announce that Manchester United's Old Trafford Stadium is now stoma friendly, and we're working with several other Premier League and Scottish Premiership clubs at present with more news to follow soon!

Tranmere Rovers and Milton Keynes Dons have also completed the adjustments needed to make sure their accessible toilets are suitable for people with stomas. The Dons announced they were a stoma-friendly club at half time during their home game against Ipswich Town back in February. You can read their media release in full on page 28.



Tranmere Rovers Stadium



Milton Keynes Dons Stadium



Stoma Friendly Tesco Extras and Superstores

Tesco have started to make the accessible toilets in their Extra and Superstore branches stoma friendly and at the time of writing shoppers in the following branches will benefit from the enhanced facilities:

- » Bournemouth Extra
- » Diss Superstore
- » Enfield Southbury Road Superstore
- » Portland Easton Superstore
- » Prescot Extra
- » Swansea Pontardawe Superstore
- » Watton Norfolk Superstore
- » Uddingston Superstore

Team Colostomy UK News

Our Rugby League team had a brilliant first game of 2023 when they faced the reigning Physical Disability Rugby League Champions Leeds Rhinos in a friendly at the South Leeds Stadium in March.



An enthusiastic crowd including supporters of Hunslet and North Wales Crusaders who were playing in the second game of the day saw an entertaining match, which ended in a narrow 16-8 win for Leeds. Huge congratulations to our boys and girls for matching such a high-profile team.

By the time you read this, we will have played our second game of the year against St Albans Centurions, at the New River Stadium, Wood Green, North London and will be gearing up for a huge game on 4 June against the British Asian Rugby Association at the home of Batley Bulldogs in West Yorkshire, in a curtain raiser to the championship game between Batley and York Knights. It's part of the Jo Cox memorial weekend which honours the former Batley & Spen MP who was sadly killed in 2016.

The game also supports our efforts to raise awareness of our charity across all communities in the UK, by focusing on the South Asian population.

Team Colostomy UK were formed back in 2018 to prove that a stoma is no barrier to playing even the toughest of contact sports, and five years later we're proud of how we're challenging and changing the perceptions that exist in some parts of society.

You can find out more about Team Colostomy UK including future games at www.ColostomyUK.org/active-ostomates/team-colostomy-rugby-league or if you're on Twitter or Instagram you can follow the team's pages [@teamcolostomyuk](https://twitter.com/teamcolostomyuk). We would love your support!





PRESS RELEASE

Stadium MK announce the opening of Stoma friendly toilets

Stadium MK is pleased to announce the opening of their Stoma friendly toilets as the Club continues the goal to provide access to all.

As part of Level Playing Field's Unite for Access campaign, Stadium MK is set to launch and open brand new Stoma friendly facilities on Saturday 25th February. The facilities will provide a safe, clean space, with clear signage, as well as supporting those with additional needs as Stadium MK aims to raise the public awareness of the stigma many Ostomates face.

It is estimated that one in 335 people in the UK have a stoma. Often referred to as ostomates, these people (who can be adults and children) have a 'hidden' condition. They have additional needs when using the toilet. Accessible toilets often lack the facilities to make stoma bag changing safe and easy.

Inadequate accessible toilet facilities act as a form of social exclusion, MK Dons look to combat this with the introduction of stoma friendly toilets at Stadium MK.

The Stoma friendly facilities will feature:

Hook on door – To hang clothing, handbags and luggage while changing stoma bags. This provides more space in the cubicle.

Shelf space – To enable ostomates to spread out their items easily and avoid having to use unsanitary surfaces.

Mirror – To enable users to see their stoma while changing their appliances.

Disposal bin in every cubicle – To avoid embarrassment for men and women having to dispose of their stoma bag in public view.

Accessible #stomafriendly toilet signage – To highlight the right of ostomates to use the toilet. Reduces risk of hostility for ostomates when using an accessible toilet.

Giovanni Cinque, Marketing & Campaigns Manager at Colostomy UK comments on the introduction of Stoma friendly toilets at Stadium MK:

"Confidence in the knowledge that suitable toilet facilities will be available if needed is life changing for many people with a stoma. It gives them the confidence to do many of the things we take for granted from attending football stadiums and entertainment venues and meeting a friend for a coffee or going shopping. So we are delighted that the accessible toilets at Stadium MK are now stoma friendly. Over 200,000 people in the UK currently live with a stoma and we look forward to working with Stadium MK to encourage as many of them as possible to attend this superb stoma friendly venue".

For more information of Stoma Friendly toilets, please visit www.colostomyuk.org/campaigns/toilets

For more information on Stadium MK visit www.stadiummk.com

Get your Stoma Aware pack and help us make a difference

Can you help us to make your community become more **#StomaAware**?

Our Stoma aware pack includes some great resources to help you engage with local businesses and organisations including:

- » Stoma Friendly Toilets letter
- » Stoma Aware Info poster
- » Stoma Friendly Toilets guidelines

To get your pack, email GetInvolved@ColostomyUK.org and help us make a difference!





fundraising



Giovanni Cinque
Marketing & Campaigns Manager
GetInvolved@ColostomyUK.org

Thank you to everyone for their kind donations. Every £1 you give really makes a difference.

We wanted to say a special thank you to the family of the late Jeanette Salisbury for their kind support of our Stoma Helpline and Befriending service.

We also know that lots of you are fundraising for us at the moment. One such person is Ruth Wilkins. Here is her story:



My stoma saved my life – now I'm giving back to Colostomy UK

I'm Ruth Wilkins. Since being diagnosed with terminal bowel cancer in 2020, I have made it my mission to raise awareness of the symptoms of bowel cancer by sharing my story and have chosen a charity each year who have supported me and my family on this journey, to raise funds for. This year my charity of choice is Colostomy UK.

Three months after diagnosis I had a blockage and after a big operation, my colostomy was created. This truly saved my life and I am so grateful to the surgeon and team who gave me this gift, and at the same time, he cut all the cancer out that he could see. Currently there is no evidence of disease, so I want to use my time raising awareness to save others.

1 in 335 people in the UK have a stoma, but until you have one, I guess it doesn't even enter your head about what it is or the challenges it can bring to people. I didn't even know what a stoma was before my operation.

Life with a stoma is sometimes a challenge: physically, emotionally and mentally. Everyone is different, and I consider myself extremely lucky compared to the experiences some people have. Colostomy UK have provided so much information, guidance, support, to me and others living with a stoma, which is why I've chosen them as the beneficiaries of my 2023 Fundraising activities.

My first challenge this year was to do 100 squats a day in February, (2800!!!!). I am so pleased and proud that many of my family have chosen to join us in this activity. We are split across the country from Swindon, Bucks, Nottingham and share a JustGiving page

Please donate to this great cause if you are able. justgiving.com/page/ruthwilkins20234colostomyuk

Thank you, Ruth Wilkins



FREEPHONE STOMA HELPLINE: 0800 328 4257

Please support Colostomy UK

Your donation to Colostomy UK will make a real difference and help us to better support more people living with a stoma, like you. Please consider supporting us by setting up a regular direct debit (see reverse page), or a one off gift by debit/credit card or cheque. Thank you.



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

Date of surgery: Reason for surgery:

Tick as appropriate: I would like to be kept informed by: ☐ Post ☐ Email

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):

- ☐ 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 The Data Protection Act 2018. 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.)

My one-off donation

- ☐ £25 ☐ £30 ☐ £50
☐ 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

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☐ 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: / / 2023

Please fill in this form to make a donation. Check your details are correct, then return the completed form by post to: Colostomy UK, 100 Berkshire Place, Winnersh, Wokingham, Berkshire, RG41 5RD. Telephone: 0118 939 1537 if you have any queries.

Registered Charity No: 1113471



Registered with
FUNDRAISING
REGULATOR



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

Charity Name:

Colostomy UK

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

Title

☐ Mr ☐ Mrs ☐ Ms ☐ Other (please specify)

Name

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

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
- 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.



Andy Wakefield: I Wanted to Live to See My Daughter Grow

BY RICHARD BIDDLE

Three years ago Andy Wakefield had an emotional overload of seismic proportions. On the day his first child was born he found out he had rectal cancer, which had invaded his prostate.

Andy experienced a rollercoaster of feelings as happiness, joy and relief, and the dawning of new responsibilities, competed with shock and fear about the future. When most new parents are thinking about how they are going to cope with months of sleepless nights, Andy was worrying about whether he would see his daughter grow into a woman, and how long he would be there for his wife. Andy is now cancer free and the proud owner of two stomas. He is fit and in a good place mentally. But getting to this point meant facing and overcoming the challenge of radical surgery, the adjustments this required to daily

life and its wider implications, which went to the very heart of what it is to be a man.

Even before his cancer diagnosis, Andy knew all about stomas. Back in 1992 when he was 12, Andy was diagnosed with Crohn's disease. In his late teens he started to have problems, which eventually necessitated ileostomy surgery in 1998. It is a period of his life that Andy remembers well. It cost him his confidence and many of his friends. After the surgery he hid away, stopped playing all the sports he loved and didn't have the social life of an 18-year-old.



The surgery stabilised Andy's condition but did not deliver the anticipated improvement. When he became ill again a few years later, his surgeon started to talk in terms of making his stoma permanent. Andy was terrified by the prospect, particularly as support for young people in his situation was so limited and hard to access at the time.

Being so ill and so young, disenfranchised Andy, making it impossible for him to advocate for himself. Luckily he had a supportive family and his mother stepped in. She insisted on a second opinion before any decisions were made. Through her research she found Professor Michael Kamm at St Mark's Hospital in Harrow. By the time Andy got to see him in 2001, Andy was physically and mentally broken. Tests were done, from which it was concluded that he was not as ill as his other medical team had thought. Under Prof Kamm's care, Andy was well again within two months and had his ileostomy successfully reversed. As an outsider looking in on this episode and setting it against what has happened to Andy more recently, one can't help but conclude that the perseverance and resilience shown by his mother and wider family ended up being a valuable life lesson.



Before and After

It stood Andy in good stead not just to face the events of 2019, but also to get his life back on track afterwards.

Between his reversal in 2001 and cancer diagnosis in 2019, Andy had 18 good years. He went to university, travelled the world, met his wife, married and settled down, and then found out he was to become a father. Throughout this period, he had regular colonoscopies. As we reported in the last edition of Tidings (see Dear Consultant) this is normal with conditions such as Crohn's where there is an increased life-time risk of colorectal cancer. Andy's case illustrates perfectly why check-ups are necessary. It was at a routine examination in 2019 that a lump was discovered which turned out to be cancer. It came as a massive shock to Andy as he had experienced none of the tell-tale symptoms (bleeding, loss of weight, tiredness).

Andy always thought the time might come when he would need a stoma again, but as a result of Crohn's and not cancer. Although still under the care of St Mark's, he was referred to a specialist surgeon, who he visited with his wife a week or so after the birth of their daughter. The surgeon explained that while radiotherapy was an option to see if it would shrink the tumour,

his best chance of survival was to have a total pelvic exenteration (TPE). This radical surgery meant having two stomas, a colostomy and a urostomy, and would leave him impotent. The couple were advised that if they wanted more children then Andy would have to freeze his sperm. Andy was also told that it would be extremely unlikely that he would be able to continue working as a personal trainer and sports therapist

because of the risk of hernias. The surgeon told him to take his time thinking about how he wanted to proceed. It's difficult, if not impossible, to imagine what Andy and his wife went through on hearing the extent of the treatment he needed and the far-reaching impact it could have on their lives. Even now, Andy struggles to put into words how it felt. He says: "It just didn't compute."

In the end, it wasn't the masses of information Andy received that helped him make the decision to go for a TPE, but his resolve to see his daughter grow. The family's new arrival was also a tremendous help in giving him the focus and strength he needed to prepare for his operation. Having her there brought clarity to his thinking and made him more determined than ever to do what was required to get better. Andy's 14-hour surgery took place in the autumn of 2019. Despite being told he could be in hospital for up to six weeks he was out in just 13 days. Knowing that his wife was having to cope with a new baby was both a big concern and a big motivation for him. After about a month, Andy was able to take a more active role as dad.

However, while Andy started to recover physically, he battled to adapt to life with two stomas. He began to fear that just as his healthcare team had warned, he would never return to the gym. He put on weight and, as a consequence, started to struggle with his body image. None of this was helped by the effect the surgery had had on sexual function. The picture of Andy with his dog was taken at this low point in his journey. His face alone speaks volumes. Andy regards his wife as his rock and her unwavering support is something that he will be ever grateful for. However, despite this, Andy started to feel angry and frustrated: 'I felt like a fraud because I could not function as a real man'.

After struggling for a year, Andy and his wife had a heart to heart. It was clear that things couldn't continue as they were. It proved a defining moment, triggering

memories of the resilience his mother had shown all those years ago and reviving his fight. Andy swore to get his life back on track. In the end this involved a two-pronged attack, which began with seeing his urologist. This in itself was a brave step, and one that ultimately proved to be a very positive one. In time it led to the restoration of sexual function.

Secondly, jolted into action by how out of shape he felt he looked in 'that photo' (taken last year on the day of his daughter's birthday party), Andy vowed to return to his pre-surgery levels of fitness. As a personal trainer and sports therapist, he knew this meant two things: training and diet. He found a coach who worked with people after surgery and together they formulated a programme. This involved three training sessions a week, working on different muscle groups, a couple of runs and some cardiovascular exercise. On the diet front he stuck to a set calorie intake each day, which was sufficient to power his exercise regime (which gradually increased in intensity), but also lose weight. If ever he started to waver, Andy looked at the photo to refocus.

Andy admits it was difficult at times, but as result he has lost 15 kgs and is now fitter than he has ever been before. His physical transformation is evident in the more recent photos you can see, as is his positive mental

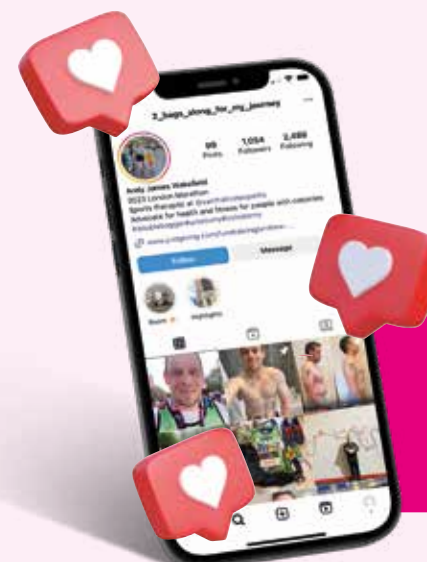
demeanour, captured in his changed expression. Despite being told it wouldn't happen, Andy is now back at work. What's more, he is also running the London Marathon in April and taking part in a number of Spartan events later this year. He has also stuck with the training programme. He says the regimented approach suits him and the focus it brings is good for his mental wellbeing.

Andy's story is one of courage and resilience. Andy is evidence that people have the capacity to triumph against the seemingly impossible. The events of 2019 and after will never be far from him, but he has managed to achieve enough distance from them to be reflective. Above all else Andy wants to use his experiences to support other people. In particular he wants to help those who are facing similarly difficult decisions about surgery or are struggling to put their lives together afterwards. From recent pictures of him, you would never know what he had been through and what he has achieved since. He has come out the other side fitter and stronger than ever before. But he is also aware that not everyone has the support he did or the motivation of a newly born daughter to push their recovery. His message though is simple: "Grasp life and never give up. Grasp all the support that is around you, including online."



@2_bags_along_for_my_journey

Andy is one of the few people with two stomas who has managed to transition to being even fitter and stronger than before surgery. He shares his journey on Instagram to inspire and show hope.





Recycle and Raise Money for Colostomy UK

We've teamed up with **icollectclothes** to offer you a hassle-free way to clear your home of unwanted items and raise money.

icollectclothes will pick up your unwanted clothing, shoes, bedding, towels, curtains, accessories (bags, belts, hats, scarves) books, DVDs, CDs, soft toys, electronics and even small domestic appliances and convert them into a donation for Colostomy UK.

Help us to continue supporting and empowering Ostomates.

If you live in London and the South, The Midlands, North West or North East, it's easy to book a collection online at: icollectclothes.co.uk/donate/colostomy-uk

In other areas, please call: 0344 879 4417.



Pancaking: Hints and Tips

Although it can hardly be called original, back on Shrove Tuesday we used Colostomy UK's social media platforms to ask people with stomas to give their tips for dealing with pancaking. Pancaking is certainly not the most pleasant part of life, but it is a reality for many ostomates. Loads of people responded and so for those readers that don't do social media, or perhaps missed all the posts, we thought it would be useful to share some of the contributions below (in no particular order):

"My experience with pancaking very much depends on the consistency of the stoma output which varies with my diet."

"Increasing your daily intake of water seems to be the number one home remedy for pancaking."

"Increase your fibre intake, this can also help alter the consistency of the stool."

"Really you need to keep the consistency of the faeces softer by increasing the fluid and perhaps fibre."

"You can also grease the inside of your bag with oil (olive oil or baby oil). This helps the stool to slide down inside the bag. Alternatively, try using a lubricating deodorant."

"Just as you apply your bag blow a little bit of air into it to prevent it from being completely flat. Towards the top of the appliance there is a filter, which allows the gas to escape. Sometimes the filter works too well and causes the bag to stick together. It is worth placing a filter cover over this (these are the little stickers that come in the box with your bags). This allows the gas to create a bit more space for the stool to move down in the bag."

"I cover the filter on the pouch with the little plaster like stickers that come in the box. By covering the filter any gas is trapped inside the pouch and usually preceding every bowel motion is a little wind, which inflates the pouch slightly allowing the motion to pass freely into the

pouch (especially if it is oiled inside). This also has the dual benefit of giving you total control over odour."

"I have dealt with it by lifting the plastic at the front of the bag, lower down than the stoma and then pushing down on the pancake with the plastic to get it away from the stoma. This seems to do the trick and allows further emissions to drop into the bag more easily."

"I have a colostomy and use adapt lubricant deodorant which helps but I put the bag inside my underwear so yes it does pancake so I empty it often and so far only had a couple of issues."



"I use stoma bridges, little sponge squares that stick inside the bag so it stays a little open. They are available from your stoma suppliers along with your normal prescription. Since discovering them I have not had any pancaking problems. If anyone wants to know more about them, I can find the order reference number."

"Leave a little air in the bag/stick a ball of tissue in there to allow space for output and reduce pancaking! Also make sure skin is nice and healthy! Any soreness will cause issues so use barrier sprays/creams or speak to your stoma nurse!"

"I use stoma bridges available from my supplier and I don't have any problems with pancaking anymore."

"A little squirt of baby oil eases all my pancake worries."

"A little bit of baby oil in the pouch."

"I definitely don't miss pancaking since I've been reversed. I do remember I used to eat a curry and it would sort it out!"

"Keeping stool soft, drink two litres water daily, otherwise use Lactulose to soften faeces. Wear a light convex flange, wear a belt. It's very difficult to overcome pancaking but try to keep faeces soft and don't get constipated."

"Drink plenty but not just plain water, alternate with cordial and fruit juices to keep output softer. Some people find convex bags help but you have to see a stoma nurse before you use them as they can cause problems if you don't need them."

"I have increased my fluid intake, oil the bag, blow air in the bag and I still pancake might try the fibre option though."

"Drinking plenty of fluid tea coffee water and fruit juice helps with the pancaking. Also try some baby oil in the top of your bag as this will help your output slide down."

"If pancaking is just stool sitting around stoma, then it's just one of those things, especially if like me you need to wear strong support pants and a Lycra wrap belt for hernias. If it leaks out under the flange then that is horrid. I hardly ever a leak – I say with fingers crossed – using Sensura Mio Convex. So just change and clean up whenever necessary. Decided pancaking on stoma is unavoidable whatever I eat or drink."

"My tip is that I blow some air into the bag before putting it on and also put baby oil in, now comes the fun bit – when I have the bag on and have it stuck on most of the way round, I leave a tiny gap at the top above the stoma. I then get a long straw and blow more air in. (I have the filters covered as this would otherwise let air out.) Then stick down the top of the bag."

"I stand facing the toilet with the seat up. Remove bag and bend over slightly in case more stool comes out. Aim my

stoma down. Then with toilet paper remove all caked stool around the stoma and in the top of bag. I repeat this every 30-60 min as I feel myself go and keep emptying it. Can't let it build up as the pressure will cause leaks on the side of bag."

"I was given some Ostomy bag lubricant/deodoriser. Each small bottle cost the NHS about £7. After it had all gone I thought, what else can I use without putting more on my order!?? Antibacterial hand gel! I get big bottles from the £1 shop and put into a smaller bottle in my changing bag. It does the same job."

"For a natural alternative, you can mix essential oil drops such as peppermint or eucalyptus into a neutral carrier oil like vegetable oil and put a drop of the mix in the bag. Lubricates as well as deodorises!"

"I also find warm drinks help soften my tummy after a pancaking episode, and if you are brave, going bagless in the privacy of home. I've sat on the loo several times massaging my tummy and it helps output a lot."



Thank you to all who sent in their tips. We hope that everyone can pick up a few new tricks! Of course, if pancaking is a persistent problem contact your stoma care nurse.

E-engage with us!



Go online to access all the support you need from Colostomy UK

Visit our website: www.colostomy.org.uk for downloadable versions of all our advice booklets, information on stoma support groups and events, the latest Active Ostomates classes and practical guidance on living with a stoma.

And while you're there, subscribe to our free, monthly e-newsletter delivered straight to your inbox.

Or connect with fellow ostomates, their family and friends in our private Facebook Group. Search Colostomy UK Support Group Facebook and click to join.

Why not share your news on Instagram and Twitter: @ColostomyUK

...and get involved!

Get Ready for Our Step Up for Stomas Challenge 2023!



Since 2018, our Step Up for Stomas challenge has become a much-anticipated event in our charity calendar, bringing together our community to raise funds and have fun along the way.

Last year, we were delighted so many of you took part in our Step Up for Stomas 39 Challenge, and we hope you'll join us once again this September, for our brand-new Step-Up challenge!

We'll be announcing the details from June onwards, so make sure you keep checking our website and social media posts for all the information you need to sign up and get ready.

There'll also be a guide and a sponsorship form in the next edition of Tidings.

Let's make this year's Step Up for Stomas the best year ever, so we can continue to provide the practical and emotional support for thousands of people throughout the country, before and after their stoma surgery.

Details announced from June onwards - keep an eye on our website & social media!





volunteers



Maxyne McGinley
Volunteers & Community Manager
Maxyne.Mcginley@ColostomyUK.org

Travel Tips and Advice

As you will see on page 46 Richard, Editor of Tidings, was recently welcomed to the quarterly support group meeting of CUPID West Dorset by our volunteer Bernard Tinker. Richard reported back that 'Travel' remains a hot topic. It therefore seemed an ideal time to ask our volunteers for their tips and advice, collecting them altogether in the summer edition of Tidings.

Additionally, as some of you are probably aware, new security scanners are in the process of being installed in many UK Airports. Our understanding is that these will be a positive development for people with stomas. Unfortunately, we didn't have the full details from the Civil Aviation Authority before going to print. As soon as we know more, we will update everyone via our website and Tidings.

Thank you to Helpline volunteers Morag Sinclair, Ros Thomas, and Moira Hammond for what follows. I'm sure there will be a nugget for even the most experienced of travellers!



Passport

- » Have at least three months to run on return (check destination country website).
- » Take a photo of your passport details on your mobile phone or print a copy to take.



Travel Insurance

- » Make sure that it covers your stoma and any other medical conditions.
- » Use comparison websites to find the best cover.



Booking

- » Always book an aisle seat on plane or train as easier to get to the loos.



Travel Certificate and paperwork

- » Colostomy UK can provide a Travel Certificate.
- » Take a paper copy of your prescription.
- » Possibly an explanatory letter from your stoma nurse explaining the quantity of stock, if your stoma needs a lot of products.
- » Photo ID Card.
- » Carry stoma pouches in hand luggage, some pre-cut for the journey. Enough for holiday and spare for emergencies/delays. Carry disposal bags and wipes in hand luggage and hold luggage. Divide a similar quantity between travel companions travel luggage and hold luggage.
- » Pack scissors in hold luggage (NB - check if rounded end scissors are OK for hand luggage). Children's craft scissors make a good alternative instead of metal ones and can be purchased abroad easily.
- » If using closed pouches, take a few drainable ones in addition to usual supplies in case of upset tummy. Carry medication for upset tummy and rehydration sachets, e.g. Dioralyte and Loperamide.
- » Small size (mini) pouches for swimming/water sports, are good for approx. two hours.
- » If you need extra wipes, save quality table napkins, they can be used wet and do not disintegrate. They make a handy towel in case of changing when out too.

Contact Details (phone/email)

- » Stoma care nurses.
- » Suppliers/delivery companies.
- » Travel insurance company.
- » Credit card providers.



At your destination

- » Store pouches in a cool place, excess heat can make the adhesive tacky and may not adhere properly.
- » Use disposable bags in hotels, apartments, on boats etc. Some cruise lines have special disposal bins, enquire when booking.
- » Be careful with ice in drinks, some countries water supply is not as good as others.



Airport

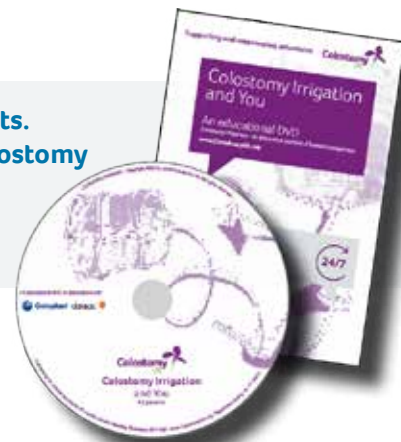
- » Light diet the day before travel.
- » Request airport assistance, if required, at time of booking.
- » Sunflower lanyard can be worn to alert staff that you may require assistance.
- » Change/empty drainable pouch before passing through security.
- » Pick up free perfume/aftershave samples in duty free; useful if you need to change your pouch on the plane.
- » Put your clean disposal bag into the sink open ready to receive your used pouch. Dispose of it in the waste bin.
- » Gummy sweets – wine gums, marshmallows will help to reduce wind in your pouch pre and during flight.



Colostomy Irrigation and You DVD

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

Note: Not all colostomates can irrigate. It is therefore essential in the first instance to consult your surgeon/stoma care nurse as they will advise as to your suitability.



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

Colostomy UK, 100 Berkshire Place, Winnersh, RG41 5RD

Title: _____ ☐ I enclose a cheque or postal order made payable to Colostomy UK

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

Address: _____

_____ Postcode: _____

Tel: _____

Email: _____

Card number: _____ (Maestro only)

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

Signed: _____ Date: _____

Also available to purchase online at: www.ColostomyUK.bigcartel.com

Please allow 30 days for delivery.

Colostomy UK, 100 Berkshire Place, Winnersh, RG41 5RD | Charity No. 1113471 | VAT No. 917079312

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

Ensure you always have access to a toilet by purchasing a Radar Key and Photo ID card. Through the National Key Scheme, Radar keys open the doors to over 9,000 accessible toilets in the UK in places like shopping centres, pubs, cafés and department stores.

A Colostomy UK Photo ID card, which is endorsed by Disability Rights UK (and displays their logo), can be helpful if you need to use accessible facilities urgently, particularly if they aren't part of the National Key Scheme.

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

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

Title: _____ Address: _____

Name: _____

Tel: _____

Email: _____ Postcode: _____

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

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

Please **tick** as appropriate:

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

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

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

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

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- 1 hour delivery window with text message update so you don't have to wait in all day
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Your Letters and Emails

Editor's note:

Thank you to everyone who has been in touch since the last edition. In fact, almost as soon as the spring edition hit the doorsteps, people started to contact us! Here is a selection. Please keep those letters and emails coming.

Dear Editor,

In the Spring 23 edition of Tidings there is an article about having a colonoscopy via the stoma. I have had this procedure three times now and have had not a single problem. I wear drainable pouches in the lead-up to the procedure, very practical when taking the gunge! Also, the procedure has been done through the drainable bag without any problems whatsoever. So, not something anyone should need to worry about I think.

*D Henderson,
(PS, I am 79
years old)*



Dear Editor

I had an emergency stoma formed following a perforated bowel during endometriosis surgery in 2014.

I lead an active life and still work as a qualified nurse in a busy area of a large hospital.

I wanted to share my experience of forgetting an essential part of my irrigation kit when travelling to Spain in 2022. Before covid I was a seasoned traveller and always made sure I carried everything I needed for my stoma in my hand luggage (extra baggage allowance can be requested by all airlines prior to flying). But in the excitement of my first post-covid holiday I was a little forgetful.

On the first day of my holiday I confidently set up my irrigation kit in the hotel bathroom, only to find to my horror I was missing the base plate. I felt very panicky because without being able to irrigate daily I would need triple the number of stoma bags. What was I going to do for 14 days travelling around Spain?

My level-headed partner came up with the solution: Why didn't I look up my stoma bags on the internet, get the order reference and try a local pharmacy?

In fact, I found all the codes and references for stoma bags and the irrigation kits on the Internet. In the second pharmacy in Malaga, I showed the one English-speaking pharmacist the pictures and codes on my phone. He found the irrigation kit and ordered what I needed. It cost me about 50 euros. He also apologised that it wouldn't be ready for collection until 6pm that day. I was totally surprised since I have to wait at least three days from my normal supplier in the UK.

My advice to any nervous traveller is to make a list of your essential items, carry all stoma supplies in your hand luggage and if you forget or are running short of stoma bags try the local pharmacy.

Julie, Salford

Hello

I was diagnosed with Pneumatosis Coli 25 years ago. I know it is a very rare condition causing gas-filled cysts in the bowel. After being ill for years and after so many treatments including having oxygen every day nothing worked. I would have terrible diarrhoea or constipation and not go to the toilet for weeks.

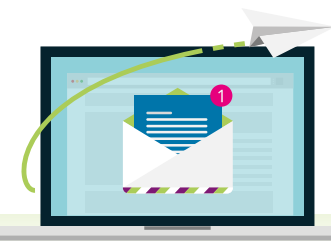
I was referred from Northampton General Hospital to John Radford at Oxford where I was told if I didn't have an operation to remove the part of the bowel affected I wouldn't survive the year. I went into hospital in October 2020 and was there for six weeks. For four weeks I was fed intravenously to build me up.

After the operation I had a stoma having lost two thirds of my large bowel. I have never seen any reference to my condition and wonder if you have heard from anyone else?

Thank you, K Coulson



E-Mails received in response to Mr B N's letter the last edition



Dear Editor,

At last, someone who has the same problem as me. I had a colostomy five years ago and have suffered occasionally from pain - akin to childbirth! - followed by violent explosive complete evacuation of the bowel similar to having taken a bowel prep for surgery.

Like Mr BN, no one seems to have an answer or have had it happen to them. Thankfully I have either been at or near home when this has happened and also know that if the pain starts, I need to find somewhere appropriate quickly. I dread this starting in the middle of John Lewis! My life is limited by fear although cruising does provide a decent holiday with little worry.

J King

Dear Editor,

After reading Mr B N's letter in issue 69, I wonder if he has been tested for bile acid malabsorption (BAM)?

His symptoms suggest he is maybe suffering from BAM. I have had this condition since having gall bladder removal and pancreatic problems which lead to surgery to form a permanent stoma. My symptoms of BAM are severe but after having a SeHCAT scan and getting a diagnosis I have been prescribed bile acid binders.

Bile acid malabsorption isn't rare but seems to often go undiagnosed. It took quite a while for me to get help. It is a horrible, debilitating condition and severe cases are now recognised as a disability. I feel for Mr B N and suggest that he requests a SeHCAT scan. It can give a conclusive diagnosis either way.

I hope this helps in some way.

Kind regards, Christine

Hi

You don't feature disasters in the magazine.

I have had several in the 14 years of having a stoma, the latest being the worst.

Flight home of 12 hours, all went well for the first ten. Had two meals on plane which included prawns. Should have known better. Changed bag after 8 hours all is well. After about 9 hours started getting that feeling in my gut. Changed bag again. Went back to seat, pressure increasing. Due to land and bag started leaking with the most abominable smell, apologised to the young girl in window seat. Worked in oncology so we discussed this. Very fortunately the middle seat was vacant thank God.

So plane pulled up to stand, my gut is trying to empty. Got off plane praying for disabled toilet, but none till I got into airport nearby passport control. Found a disabled toilet which was vacant. Went in, stripped off and tried to clean up. Threw my vest in the bin. Eventually got something like respectable. One issue was basin tap was a sensor type, useless in my predicament. Needed a tap.

Through passport control holding bag firmly I had replaced in toilet, collected luggage and met my son. It was a relief not to face the tube and train for two hours. He is very aware of my condition and accepted the smell, etc.

Phoned home, told them to open front door and stand back. Straight into shower, cleaned clothes and myself.

Moral, don't eat prawns!

Mike



We look forward to hearing from you, our readers:

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

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

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



News from Support Groups across the UK

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

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

Tel: **0118 939 1537** or email: **hello@ColostomyUK.org**.

Outlook, The North Staffs Ostomy Support Group

Meet around every two months at Bradwell Lodge Community Centre, Bradwell Lane, Newcastle Under Lyme, Staff ST5 8PS. Meetings are also held in Stafford.

For further information please contact Moira Hammond on **07788 402195** or email **cm.hammond@ntlworld.com**

SHROPSHIRE B.O.T.S. (Bums on Tums) STOMA SUPPORT GROUP

The Bums on Tums have moved! We now meet at Hope Church, Room 1, Market Gate, Oswestry. Meetings are still on the second Thursday of the month at 2pm, and all are welcome.

We will be holding our 7th Annual Open Day on 5 October 10:30 am – 3:00 pm at Hope Church, English Walls, Oswestry, SY11 2NR. Suppliers and distributors will be showing their products. Colostomy UK, the Ileostomy Association, the Urostomy Association and Bowel Cancer (Wales) will be present.

The ever popular BOTS Café will be serving sandwiches, cakes etc. all day together with free tea and coffee.

For more information call Irene Constable **01691 238357** or email: **ireneconstable@phonecoop.coop**.

C.U.P.I.D. West Dorset

We held our quarterly meeting on 15 April in Dorchester. Titled 'The View from the Top' our speakers were Caroline Bramwell the IA's PR & Communications Manager and our very own Richard Biddle who is well known to all of us as the Editor of 'Tidings'.

In what was a very special occasion for a very well-attended meeting, each spoke about the work they do, the help and services they provide and projects in which they are involved. Richard gave us an insight into the origins of our charity and updated us on current projects and campaigning, Helpline and befriending service and... needless to say 'Tidings'.

Caroline's talk covered the support the IA gives in respect of areas such as life improvement, peer support, patient choice on such matters as reversals and well as breaking down Taboos.

The Q & A session covered subjects such as air travel, obtaining help and information and recognition that more public awareness is required over the use of accessible toilets when "not all disabilities are visible" particularly as there are around 200,000 ostomates in the UK.

Bernard Tinker (Colostomy UK Volunteer)

Berwick Stoma Support Group

We are a small friendly group covering the Borders area, on both sides. We meet every 3rd Thursday of each month, between 10:00am – 12:00pm, in The William Elder Building, 56-58 Castlegate, Berwick-upon-Tweed, TD15 1JT.

All types of stomas are welcome as well as partners. A supplier is usually in attendance enabling everyone to see the latest products.

Any queries contact Bobbie: **07714 479320**



Ashford Stoma Support Group

Meet at 2:00 pm on the last Thursday of the month in the Community Room at Tesco Crooksfoot Store, Ashford, Kent TN24 0YE. When possible, one of our stoma nurses attends. It is a great opportunity to chat to fellow ostomates about all things stoma. Each month we have a guest speaker.

For more information contact: **Carol Hobbs carolahobbs@gmail.com** or **David Christian davidhchristian@gmail.com**

Forthcoming meetings:

29 June – Sr. Julie Bell, East Kent NHS Stoma Service
27 July – Cream Tea
31 Aug – Fittleworth
28 Sept – Consultant Surgeon East Kent Hospitals NHS Trust
26 Oct – Suportx
30 Nov – Dansac
14 Dec – Christmas party!

Mid Devon Ostomy Support Group

Next dates: Saturday 12 August and Saturday 18 November

We welcome anyone with any type of stoma. We are an informal friendly group who meet at The Boniface Centre, Crediton 2-4pm EX17 2AH. Car park at rear or easy to get to by bus or train. Join us for a cuppa, cake and a raffle!

Stoma companies, so far confirmed Clinimed 12 August, Hollister and Clinimed 18 November. There is usually a stoma nurse from the Royal Devon University Healthcare hospital at Exeter.

For more details please contact Janice: **07923975051** or **janice234ford@gmail.com**

Channel Islands

Guernsey

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

Jersey

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

England

Berkshire

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

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

Bristol

Bristol Ostomy Self Support (BOSS)
Pat T: 07855 449578
E: info@ostomy.org.uk
W: www.ostomy.org.uk

Buckinghamshire

High Wycombe Stoma Support Group
T: 0800 318965

Milton Keynes Stoma Support Group (MKSSG)
E: support@mkssg.org.uk

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

Cambridgeshire

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

Cheshire

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

Crewe & District South Cheshire Stoma Group
Venue phone number: 01270 560471

Stockport Support Group

Marion Caulfield
T: 0161 320 9400 or 0800 652 6667

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

Cleveland

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

Co. Durham

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

Darlington Support Group
Margaret Clothier
T: 0191 333 2184

Durham Stoma Support Group
Lynn Ridley
T: 0191 333 2184

Cornwall

Cornwall & Plymouth Bowel Cancer Support Group
The Secretary T: 01872 241 145
E: cbcsginfo@gmail.com
W: www.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

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: 07923 975 051
E: janice234ford@gmail.com

Plymouth & District Bowel Cancer Support Group

Rita T: 0785 557 1840
E: admin@plmdistbcsg.com



Dorset

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

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

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

Essex

Connect
Alan Marshall T: 01279 411830
E: comeconnectwithus@gmail.com

Mid Essex Stoma Support Group
Paul Fox T: 01245 441 894

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

Optimistic Ostomates
Stoma Care Team T: 01702 385158

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

Hampshire

Replummed Stoma Support Group
W: www.replummed.me

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

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

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

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

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

Herefordshire

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

Hertfordshire

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

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

Isle of Wight

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

Kent

Ashford Stoma Support Group
Malcolm Jones T: 07709 534463

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

Dover Stoma Friends Group Support
Carolyn Fullager T: 01304 821 132

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

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

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

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

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

Thanet Stoma Buddies Support Group
Kathy T: 01843 291 825

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

Lancashire

Bowel Buddies Preston
Calum T: 07463 880 652
Vine House T: 01772 793 344

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

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

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

Leicestershire

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

Lincolnshire

Grantham Support Group
Bobbie/Rachel T: 01476 464 822

London

Bowel & Other Cancer Support Newham
T: 020 8553 5366

Homerton Hospital Bowel & Stoma Support Group
Irene Fernandes and Glyn Fountaine
T: 02085105318 or 07785971120

Newham Stoma Support Group
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
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
Bob Martin T: 01744 345 365
E: contact@sthelenscancersupportgroup.org.uk

Middlesex

Inside Out
Sarah Varma T: 0208 235 4110
Bob T: 020 8428 4242
Barry Caplan (Chair) T: 07811084514
E: abmc23@virginmedia.com

Norfolk

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

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

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

Northamptonshire

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

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull T: 07714 479 320

Hexham Ostomy Group
Marie Douglas T:07941 433 600

Northumberland Cancer Support
E: members@northumberlandcancer supportgroup.co.uk

Nottinghamshire

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

Nottingham QMC Stoma Support Group
Robin Ford T: 0115 778 6463
E: hello@nottingham-stoma-support-group.uk

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

Shropshire

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

Somerset

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

Staffordshire

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

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

Suffolk

East Suffolk Ostomy Group
Ian Denison T: 01473 684865

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

Guildford Stoma Support Group
T: 01483 571122 ext 2558

Sussex

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

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

East Sussex Stoma Support Group
Vicki Blaker T: 0300 131 4603
E: esh-tr.StomaCareDept@nhs.net

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

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
Bob T: 07564 680 803
E: nuneatonstoma@aol.com

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
E: coventrystoma@btinternet.com

Wiltshire

Swindon IA
W: www.swindon-ia.org.uk

Wessex Stoma Support Group
Karen Berryman T: 01980 590 599
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
Celia Utley (Chairman) T: 01226 284 262

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

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

Bradford Stoma Support Group
Lisa Hall T: 07552 276 747

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

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

Harrogate Stoma Support Group
Stoma department office –
Nurse Gill Wilson/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 T: 07544882353
E: secondchanceostomyyorkshire@gmail.com
W: www.secondchance-ostomyyorkshire.org

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



Isle of Man

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

Northern Ireland**County Antrim**

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

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) Dublin
National Cancer Helpline
T: +353 1 800 200 700
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
Rhona T: 01294 557 478

Greater Glasgow

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

Moray

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

Scottish Borders

Stoma Support Group
Fiona Gentleman T: 01450 371 063
E: r.gentleman@sky.com

South Lanarkshire

South Lanarkshire Stoma Support group
Val McNeill T: 07903519924
E: valmcneill20@hotmail.com

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

Conwy

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

Gwent

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

Mid Glamorgan

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

Pembrokeshire

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

Powys

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

Rhondda Cynon Taf

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

Swansea

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



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