

Supporting and empowering you



# Tidings

Jane  
Bland  
reveals all...

**“..I’m now very  
comfortable  
with my stoma”**

page 28



**“ Stoma  
surgery saved  
my life ”**

Jodie's story – page 41



# *Have you joined Coloplast Care?*

*Complete the form overleaf and join today >>*

Coloplast®  
 Care



# The Ostomy Check

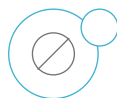


Don't accept stoma issues as part of your life. The Ostomy Check is a simple way for you to check common issues such as sore skin, problems with adhesion and leakage. Based on your answers we will make sure the information and support you get from Coloplast Care meets your needs.

Please tick in circles where appropriate

## Do you have any adhesion issues?

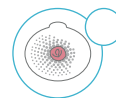
Ensuring your product sticks securely to your body helps you feel secure, and prevents complications. You can tick one or more issues.



None



Insufficient adhesion when applying



Adhesive dissolves during wear



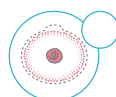
Adhesive edges roll

## Do you have any skin irritation issues?

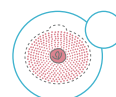
Your skin around your stoma should look like the rest of your stomach. If not, you can tick one or more issues.



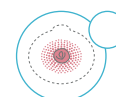
None



At the outer edge of the baseplate



Under the baseplate



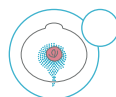
Around the stoma

## Do you have any pouch issues?

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



None



Leakage



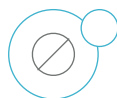
Odour



Ballooning or pancaking

## For two piece appliance users only

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



None



Coupling difficult to close or open



Pouch falls off



Leakage at coupling

## Would you like us to call you to discuss the answers you have given above?

Yes, please call me (tick as appropriate)

☐

First Name  Surname

Address

Post Code  Date of birth (DD/MM/YYYY)

\*Email

Date of Stoma Surgery  Telephone Number

Signature

\* Mandatory field. How your information will be used. By providing your personal information on this form, you are consenting to Coloplast using it for administration and analysis purposes and to enter you into the Coloplast Care email programme. We may share this information with healthcare professionals and other companies required for the delivery of your products or as required by law.

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*"Each month you reach out to people like me to ask for an update, not just in my physical health, but emotional wellbeing relating to me and my stoma. Nobody else does that!*

*Then you send out advice that I can read through at my leisure. I find this a huge help."*

Gill

## What is Coloplast® Care?

*Coloplast Care is an online support programme for people with a stoma.*

Whether you are pre or post-surgery or have had a stoma for years - we offer a helping hand by providing advice on how to solve common issues with your stoma, tips on your routine and practical advice on lifestyle including diet, travel and exercise.

All this is available to you on our Coloplast Care website and we will send you news, advice and ongoing support by email.

Please complete the Ostomy Check opposite and return using the FREEPOST address provided. By providing this information we will automatically sign you up to Coloplast Care and provide you with support should you need it, either by email or from one of our Coloplast Care Specialists (which is why we ask for your email address and phone number).

Alternatively you can take the Ostomy Check and sign up to Coloplast Care at [www.coloplast.co.uk/ColostomyUK](http://www.coloplast.co.uk/ColostomyUK)





# Dear readers



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## Cover picture

Jane Bland nude photoshoot for *Good Housekeeping* – page 28.

## Tidings Magazine:

The views expressed by the contributors are not necessarily those of Colostomy UK. Great care has been taken to ensure accuracy, but Colostomy UK cannot accept responsibility for errors or omissions.

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L-R: Billy McIntock – SecuriCare, Martin Offiah – ex Wigan, London Broncos and Great Britain  
Graham Wells & Matt Turner – Team Colostomy UK RL, Giovanni Cinque – Colostomy UK

**The summer is here and it's certainly very welcome after the terrible weather we had earlier this year. It's taken us until July to thaw out! Neither of us have experienced snow in April before but, much as it looked pretty to start with, the wonder soon wore off as we tried to negotiate our way to work...**

If you are reading this relaxing by the pool in some faraway destination, then we hope you are enjoying yourself. We'd like to join you, but there has been no let up at **Colostomy UK** – we are just as busy as ever. Our Medway Dragons Family Fun day is now just a week or so away. We're really looking forward to this and would love to see you on 21 July if you are able to make it. (to read more, see page 38). Planning is now underway for our next open day. Just like weddings, you have to do this sort of thing years in advance now. Our work with airports is ongoing and since the last update we have attended our first meeting as members of the Civil Aviation Authority's Access to Air Travel panel. We are very pleased to be involved in this as it gives us an opportunity to positively influence policies and procedures on behalf of ostomates. As we have said before, if you have had either a bad or a good experience travelling through a UK airport then we want to hear from you. On a completely different subject, we have been receiving a steady stream of queries and comments concerning the new prescribing formularies. Please keep these coming, as at the moment we don't have enough information on their impact to have an official **Colostomy UK** 'position'.

We have some really inspiring pieces in this edition. Many of you will identify with Richard Biddle's article on body image. As we all know, after stoma surgery this often takes quite a knock. In fact, in our opinion this aspect of the 'journey' hasn't had anywhere near the attention it deserves. This is why we are so thrilled to feature Jane Bland on our front cover. You can read all about her 'bags and all' naked photoshoot for *Good Housekeeping* on page 28. We have two real lives stories to captivate you further. Jodie Hookway talks about her struggles with Crohn's, the resultant surgery and being pregnant with a stoma. Don Dow, who was diagnosed with bowel cancer earlier this year, explains how he got in shape in readiness for surgery and has some advice for what not to take to hospital for the post-op recovery period. For those of you that are considering irrigation, we are confident that you will find Patrick Reeve's article useful. This is something of a back-to-basics piece as Patrick has only been irrigating a short time. As well as explaining his routine, he gives an honest rendering of the benefits, which are many given his job requires lots of travelling. Finally, as you have come to expect, there are readers' letters, updates on our campaigns and projects (and in particular the 50K Challenge), all the latest news and, to cap it all (if you will excuse the pun!) an article on Coloplast's Conseal Plug.



*Libby*

Libby Herbert  
General Manager



*Sarah*

Sarah Squire  
Trustee, Colostomate  
and Volunteer

# We deliver...



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

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

In addition, PharmaCare, our registered pharmacy service, can dispense your prescription medicines along with your appliances in one convenient delivery.

**To find out more about joining the  
SecuriCare home delivery service visit  
[www.securicaremedical.co.uk](http://www.securicaremedical.co.uk)  
or call us on  
**0800 585 125****





We are **Colostomy UK**. Here if you have questions, need support or just want to talk to someone who lives with a stoma.

Your voice on the bigger issues: advocates for your rights and campaigning to raise awareness of what matters to you; running projects to empower you; building communities to support you.

#### How to contact us

##### General Enquiries

0118 939 1537

24-hour free helpline (stoma care queries only)

0800 328 4257

[info@ColostomyUK.org](mailto:info@ColostomyUK.org)

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

0118 939 1537

[info@ColostomyUK.org](mailto:info@ColostomyUK.org)

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0118 918 0500

[arvind.anand@ColostomyUK.org](mailto:arvind.anand@ColostomyUK.org)

##### Social media:



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



@ColostomyUK

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### Donating to Colostomy UK

An annual donation of £20 (or whatever you can afford) allows us to produce *Tidings* and to continue our vital work, supporting, and empowering ostomates – see page 47 for donation form.

You can donate via our website [www.ColostomyUK.org/donate](http://www.ColostomyUK.org/donate) or by calling us on 0118 939 1537

# Bulletin Board



Clare Matthews – Marketing and Communications Manager

## Your voice on the bigger issues

**Here at Colostomy UK we are constantly striving to ensure that the rights and needs of ostomates are represented in society. Alongside our core support services we are working hard with airports and other business and organisations to get your voice heard.**

On these pages you will find more about our recent work with the Civil Aviation Authority to ensure airport travel is as hassle free as possible. You will also find out more about our campaign for stoma friendly toilets. We'd love your support campaigning too, so if you'd be happy to speak to organisations and businesses in your local area about how they can become stoma friendly, please contact Clare Matthews: [Clare.Matthews@ColostomyUK.org](mailto:Clare.Matthews@ColostomyUK.org). We are advocates for your rights so if you have experienced difficulties when travelling through any UK airport or with toilets and would like our help please contact us by email at: [info@ColostomyUK.org](mailto:info@ColostomyUK.org) or on: **0118 939 1537**. ■



## Sainsbury's – training staff on hidden conditions

Last month we worked with Sainsbury's to help them produce a film to be used to educate staff on hidden conditions, accessible toilets and inclusivity. Our volunteer, Colin Allum, was filmed laying out his stoma supplies and talked about his stoma, his experiences of accessible toilets and the importance of a shelf, hook, bin and inclusive signage. Our Marketing and Communications Manager, Clare Matthews, then talked more about what a stoma is, our campaigns and the importance of recognising hidden conditions. We can't wait to see the finished production. ■



**World Ostomy Day** is celebrated every three years and aims to raise awareness of stomas around the globe. This year it will be held on Saturday, October 6, 2018. For Colostomy Day this year we will be joining and supporting World Ostomy Day. This year's theme will be 'Speaking Out Changes Lives'.

We are teaming up with the Ileostomy and Internal Pouch Support Group (IA) and the Urostomy Association (UA) to speak out about stomas. You'll be able to find us on a World Ostomy Day branded bus, driving around the streets of London. Our destination will be Speakers' Corner in Hyde Park where ostomates will be saying their piece and 'speaking out'.

Further details will be available on our website and social media nearer the time. If you are not online and want to find out more, then please call us in the office on: **0118 939 1537**. ■

## Team Colostomy UK Rugby League

We're excited to announce that **Colostomy UK** have formed a Rugby League side 'Team Colostomy UK' who will be making their debut against the Medway Dragons Masters team as part of a new partnership. Find out more on page 38. ■





## Stoma friendly airports



You may have read in the last issue of *Tidings* about our work with Manchester Airport – 'Have Bag, can travel'. We're pleased to say that since we have been engaging with the airport we have seen a 66% drop in the number of complaints we have received about Manchester, compared to the same period last year. Our engagement with them continues through their quarterly Accessibility Forum where **Colostomy UK** and other 'hidden conditions' charities have the opportunity to share concerns with security and customer service staff, and input in to future plans.

In February we met with James Freemantle, The Consumer Enforcement Manager at the Civil Aviation Authority (CAA). This gave us the opportunity to share with him our airport engagement so far and also seek advice on how we can further develop our airport strategy. As a result of our meeting with James, Libby

Herbert has been invited to sit on the CAA Access Panel. The Access Panel meets twice a year and advises the CAA on policy issues in the area of impairments, hidden conditions and disabilities.

We have also been invited to join the Heathrow Accessible Transport Forum (ATF) and attended our first meeting in April. The ATF is part of the Heathrow Access Advisory Group whose key objective is to bring accessibility and inclusion to the forefront of Heathrow's agenda. The purpose of the ATF is to provide a grass roots connection with the people who require additional support when flying through Heathrow.

In June we met with Sara Marchant The Accessibility Manager for Gatwick Airport, to discuss how we can work with them to improve the travel experience for people with a stoma using their facilities. ■



## The ileostomy & internal pouch Support Group

Listen • Inform • Support

## IA national council meeting

In April our General Manager, Libby Herbert, attended the IA (Ileostomy and Internal Pouch Support Group) National Council Meeting in Ashford. Libby was delighted to be invited to attend and received a very warm welcome. The event gave Libby a chance to meet with lots of key people in the stoma industry and to forge stronger links with our tri-charity partners at the IA and UA. ■

## Can you help?

**Colostomy UK** and Wexham Park Hospital are looking for potential volunteers to help with the launch of a new support group for ostomates. If you live in Ascot, Bracknell, Maidenhead, Slough, Windsor or South Buckinghamshire and are interested in helping out please call Giovanni Cinque on:

**0118 939 1537** or email:

**Giovanni.Cinque@ColostomyUK.org**

## Dementia and a stoma

Following on from the launch of our *Caring for a person with a stoma and dementia* booklet, we're proud to say that **Colostomy UK** is now a registered Dementia Friends organisation. All staff, trustees, and volunteers will also be given the opportunity to attend Dementia Friends Information sessions, which will teach them about what it is like to live with dementia and some of the small actions they can take to help those living with dementia in their communities.

In March we were invited to Join the inaugural Windsor, Ascot and Maidenhead Dementia Action Alliance alongside organisations including Care UK, Age Concern, The Alzheimer's Society, The Royal Borough of Windsor and Maidenhead, The Royal Collection, Metro Bank, and Waitrose. Its aim is to promote a dementia-friendly community within the Royal Borough of Windsor and Maidenhead. ■



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# Getting fit to get fitter

**In this article Don (73) tells us all about how he lost weight and got as healthy as possible before his stoma surgery.**



Don Dow

**It all started in late December 2017 when I discovered some blood in the toilet. I decided to make a GP appointment to check this out and at the same time see him about my enlarged prostate which was causing regular night time toilet visits. Initially, I was diagnosed with an infection and prescribed a course of antibiotics. But, with the Christmas period over and my antibiotics completed, blood was still appearing in the toilet bowl, so I returned to the Doctor for more advice.**

The Doctor arranged for two sets of bloods: the first for the rectum investigation; the second to check problems with my enlarged prostate (thankfully the test showed it was benign). I was also referred to the Endoscopy Department for an internal investigation. At the end of this I was given the bad news: bowel cancer. It also revealed that I had a large Polyp growing in a position the consultant could not get to. I was advised that surgery for the cancer was necessary and told by the consultant that I needed to lose weight and get as fit as possible prior to this. I was also asked to return for a second colonoscopy investigation, during which the 30 cm long polyp was removed.

At the meeting with the consulting surgeon, the risks of the proposed surgery were explained together with the options. He hoped to cut out the bowel cancer which was very low down in the pelvis area and, after removing the tumour, join the colon ends together. But the risk of infection was great. The other alternative, if the first

proved impossible, was to remove the tumour and connect my colon direct to a stoma with a permanent colostomy bag.

I now moved into the first stages of the pre-op assessments and awaited my operation date. Over the next five weeks I set myself a target to lose some weight and get fit. I cut out all fatty foods and ate as healthily as possible. I had given up alcohol the previous December which helped with the weight loss and my pocket! I made a good start to each day with rolled oats porridge (made with water) and topped with pulsed pears, grapes and two large spoons of zero fat Greek yogurt. I also walked briskly every day and over the period walked more than 80.5 Km. The result was I lost a stone in weight.

I had my surgery on 14 March this year. Due to complications the surgeon had to carry out the full operation (called an Hartmann's Procedure). This resulted in a permanent colostomy. I also ended up with an infection after the operation, which took time to heal. My post-op recovery time in hospital was quickened by the nurses, doctors and surgeons, all of whom were simply fantastic. Initially my bowels stopped functioning and so the surgeon encouraged me to get up and exercise. I did this by walking the ward corridors and within a few days my system started working again.

I thought I had prepared well for my hospital stay, packing a drawing pad and pencils and a couple of books to read. I also had e-books on my phone. The reality was none of it was used and my wife eventually took the whole lot home. Although my wife

or daughter brought me in a daily newspaper, most of the time I just scanned the headlines as I couldn't concentrate on the small text. The most useful item was my pocket dab radio with ear phones. I listened to this during day and at night, with an eye mask to reduce the hospital lights. I also enjoyed brief chats with fellow patients.

After nine days in hospital I came home but had ongoing rectum drain problems due to the infection. I also had an infection in one of my surgical wounds and so was put on antibiotics. This meant that to begin with I had to go back to hospital each day for new dressings. I have now learnt that the rectum drain problems can be ongoing due to the natural build up of mucus. I am very grateful for all the information I received from **Colostomy UK**; amongst other things, I found their booklet on rectal discharge very useful.

My enlarged prostate is the next problem to tackle. This still has me up at night, sitting in the kitchen with a cup of peppermint tea, hoping that it will help me to pass water. I am hoping that this can be resolved with tablets, although those prescribed so far don't agree with me.

With my operation over, I look forward to a great future. I am hoping to get back to my art hobby. Just before my surgery I sketched and prepared portraits of my three grandsons. I plan to complete these in acrylic paints and hope to achieve a good likeness!

**Don Dow**  
10 April 2018

# FINDING MY PERFECT BAG WHILE PREGNANT WITH TWINS



**With a family of four, and soon to be six, pregnant 37-year-old Stephanie Cowie was using two types of bag. One because she liked the aesthetics, the other to soothe her sore skin after using the former. She couldn't find the perfect bag that did everything...until now.**

Working mum, Steph, was diagnosed with ulcerative colitis during her second pregnancy. After deciding she needed to be well again for her growing family, she made the brave decision to have a stoma formed. Steph likes to research and test bags and isn't afraid of trying out new things.

She said: "After trying lots, I settled down with two brands and alternated between them. I liked one product due to its aesthetics, but it affected my skin badly. I liked the other, the Salts Confidence® Natural Advance because it soothed my sore skin. It wasn't ideal having to swap between two different bags but at least I had found a temporary solution."

Steph then noticed the new Salts Confidence® Be range via social media. "I remember saying – three colours, no way... is that a hoax? I thought it looked like an item of clothing, it certainly didn't look like a medical device."

Confidence® Be closed bags are available in black, white and stone so you can choose the colour of your bag to match your mood, outfit or underwear.



Having a choice of colours is a real first for people living with a stoma. Confidence® Be comes in black, white and stone, so Steph can match it with underwear, swimwear or clothes and have the confidence to wear what she wants.

Steph really wanted a comfortable bag that fitted well on her tummy which had really changed shape! "I love Confidence® Be. I immediately felt the difference. It's lighter in weight, it doesn't pull on your skin and I love the different colours. I was really interested in the 'anti-sag' feature given the shape I am at the moment. It is everything I want a bag to be. It's a game-changer, a life-changer."

Salts Confidence® Be has also been designed to look great, no matter how long it's worn. The new and improved fabric stays sleek, without bobbling or fraying over time. While smart, anti-sag stitching helps the bag keep its shape and prevents drag, even when full. Giving everyone the confidence to enjoy the most important things in life.

"Confidence® Be is going to help me do that. Whether I wear white or black, I will feel good and positive. I know it will work, it won't hurt my skin, it is easier to use. It doesn't sag, it looks great, what's more to say. I used to use two different bags, now I only have to wear one. I have found the perfect solution."



## Try Confidence® Be for yourself.

You can order samples today on freephone: **0800 028 2144** (England & Wales), **0800 626388** (Scotland). Alternatively, you can email: [samples@salts.co.uk](mailto:samples@salts.co.uk) or visit [www.salts.co.uk](http://www.salts.co.uk)



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**CONFIDENCE® BE**  
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# Your rights regarding your NHS prescription and the Electronic Prescription Service (EPS) for England only

**This article was written and approved by the Patient, Industry and Professionals forum (PIPs) who are committed to improving products and standards of service.**

## NHS prescriptions

The NHS do not allow prescriber's to direct a prescription to a particular dispensing contractor ie a Dispensing Appliance Contractor (DAC) or a Pharmacy. Remember, a prescription belongs to you, not the GP, you decide who will dispense it; no one can tell you who to take it to. If you feel you have had your prescription directed to a particular contractor you should contact your usual dispenser, your specialist nurse or your patient association (**Colostomy UK**, IA and UA)

## Electronic Prescription Service for England only

You may now be becoming more aware of EPS as GPs start to issue prescriptions electronically. Uptake is now very high with 92.4% of GPs now sending electronic prescriptions. In fact 61% of all prescriptions issued in 2017 were sent electronically.

Using EPS has a number of advantages for both you as a patient, for prescribers and dispensers:

- ❖ Transmission of the prescription is very quick, almost instant, it is certainly quicker than your GP posting your paper prescription.
- ❖ It's easier for the GP as electronic prescriptions can be signed electronically.
- ❖ It's easier for your dispenser as it is quicker to process and submit to the NHS.
- ❖ It's safer as your prescription is less likely to get lost.
- ❖ It's more efficient and less wasteful, there are not millions of paper prescriptions being printed and then bundled up and sent to the NHS for payment.
- ❖ It's more accurate – as there are less people typing and inputting information, fewer mistakes are made.

### How does EPS work?

You chose who dispenses your prescription,

this is called 'nomination'. You can choose up the three dispensers:

- ❖ You can nominate a pharmacy for your medicines and if you wish they can also dispense your appliances.
- ❖ You can also nominate a Dispensing Appliance Contractor (DAC) for just your appliance prescriptions to go to. This will be your prescription for stoma bags, catheters, sheaths, wound care and similar items.
- ❖ If you live in a rural area you can also nominate your Dispensing Doctor's surgery.

Remember, with both paper and electronic prescriptions, the prescription belongs to you and you can take it to, or nominate any dispenser, anywhere in the country. A prescriber or any other health care professional cannot tell you where you must take or send it.

### How do you make a nomination?

You can nominate your dispenser at your GP surgery, at a Pharmacy or ask your DAC to do it. They may want you to sign a consent form as a record of your request so that they have proof of your choice. They will then update the EPS system and whenever your GP writes a prescription for you, it is sent automatically to the dispenser/s you have chosen. It is very simple.

You can change your nomination at any time and this will change where any prescriptions are sent. As of March 2018 over 45% of the population of England have sent up a nominated dispenser.

EPS works well with repeat prescriptions. If you have the same appliances month after month, rather than contacting the GP every time, they can upload 6 or 12 prescriptions into the system. As each one is used, the next one is made available automatically. The dispenser **MUST** contact you each time they use a prescription to make sure you need the items and your condition hasn't changed – a sensible measure to prevent waste and over usage – but this really is no different to best practice with paper prescriptions.

If you haven't used an electronic prescription yet, then speak to your GP or your dispenser.

**Remember, you can have a different dispenser for your appliances to your medicines and the prescription is yours, so you can send it wherever you want!**

## What about Scotland and Wales?

Scotland and Wales have their own NHS and they decided that they would introduce electronic prescriptions differently. They still issue paper prescriptions that are bar coded, much as EPS Release 1 in England.

At present, in Scotland and Wales, appliances can't have any form of electronic prescription and DACs or Approved Stoma Suppliers (in Scotland) are not enabled to use EPS. ■

## Your prescription is yours and you decide where it gets dispensed

**You can decide how to get your prescription supplies dispensed.**

You can obtain prescription supplies in five different ways:

- i. You can let the supply company (sometimes called DACs) handle everything – you place an order with them and they will contact your GP to get the prescription.
- ii. You can place an order with a supply company and then send them your prescription yourself.
- iii. Your GP can handle everything – you can ask your GP to send the prescription to your supply company of choice. Some GP practices also have a dispensing arm that may be able to provide your appliance.
- iv. You can order on the NHS Electronic Prescription Service (EPS) via your GP or nurse. You will need to nominate your supply company and prescriptions will be sent there electronically, reducing delivery time.
- v. You can take your prescription to a local pharmacy.

**Unfortunately it varies and some GPs don't deal with a DAC or send the prescription, however it is always worth asking the question**

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# Just how important is body image?



Richard Biddle – Writer and Researcher

**Ever walked past a mirror and copped a sneaky glance...just to make sure you look 'ok'? I certainly have and usually regret doing so. I always seem to have a white and spiteful look about me. The combination of office work and limited sunlight makes it difficult to achieve that tanned look deemed so appealing. But why do we do the mirror thing? I'm sure the media has something to do with it. Everywhere we are confronted by images of beautiful people. There's always something to aspire to, whether it be an ideal weight, body shape, complexion or 'look'.**

The fashion industry is now worth an estimated £28 billion to the British economy. Cosmetic surgery, once the preserve of Hollywood film stars is now commonplace. So too, is body piercing. Ten years ago a study in the *British Medical Journal* reported that one in 10 people (and nearly half of all young women) had a body piercing other than an earlobe. A measure of just how popular this sort of body 'enhancement' has become is the burden it has placed on the NHS – sorting out botched jobs. Tattoos are also, once again, in vogue. According to an article by Tessa Dunlop in *History Today*, the number of tattoo parlours in Britain increased by over 500% between 2000 and 2012. Then there are all the gyms and spas...society, it seems, is obsessed. And, far from being a modern, media-driven phenomenon, I would argue that this has always been the case. The British Museum's recent exhibition of artifacts from ancient Pompeii and Herculaneum revealed an enduring

fascination with how we look. Like it not, how you feel about your body and the way you look, is important. It has implications for how you behave, your chances of getting a job, your chances of finding a partner, mental well-being, the list is endless.

So what happens when you become ill, so seriously ill that part of your treatment involves body-changing surgery? This is the case with people (ostomates) who have undergone stoma surgery. Used in the treatment of diseases such as bowel cancer, it involves making an opening in the abdomen (known as a stoma) through which bodily waste is diverted and then collected in a bag. Although to others the condition may be 'invisible', the impact on the person concerned can be devastating. Perceptions of being unattractive can rapidly lead to social isolation and have a frightening effect on intimate relationships and sexual function. In **Colostomy UK's** life style survey (2016) almost two thirds of respondents said they felt that their body image was worse following surgery. Even more concerning, was the handful of people who admitted to having felt suicidal. These findings resonate with a study published in the *British Journal of Nursing* in 2015. This suggested that after stoma surgery many people go through the grieving process of loss, denial and anger, as they mourn the 'death' of their old self.

Studies show that good pre-op preparation followed afterwards by ongoing professional and lay support (such as that offered by patient associations and

charities), along with access to quality information play a vital role helping ostomates come to terms with their altered body image. But, from my own involvement in supporting patients post-op, I know that small things can make a huge difference too. One example of this is knickers and, I should add, knickers on prescription. I don't mean 'national health' knickers either, like the old 'national health' glasses, but knickers which, as well as performing a medical function, make the wearer feel just a little bit better about themselves.

When I say this, people quite often raise their eyebrows. Silently, they're thinking: "Whatever next?". If this is you, then have a read of a recent blog by Rachel Jury called *Body Confidence With a Stoma*. In what can only be described as a piece from the heart, the author talks candidly about the effect stoma surgery has had on her life. It's powerful stuff. It also includes testimony from other ostomates. The one that sticks most in my mind is from a lady who, as a result of developing a parastomal hernia after surgery, now has to wear maternity clothing. This is something she struggles with because, amongst other things, it constantly reminds her that she can no longer have children. If you were this lady's GP and she came to you in the hope of getting a prescription for some support underwear, and had the audacity to expect something a little pretty into the bargain, would you deny her?

This article was first published on [huffingtonpost.co.uk](http://huffingtonpost.co.uk) on 28 March 2018. ■



Giovanni Cinque – Fundraising and Development Manager

# Care needs assessments explained

**Recently we have had a number of calls to our helpline from ostomates seeking advice as they are struggling to manage their care needs in their own home.**

If you need help with everyday tasks, then your local authority has a legal duty to carry out an assessment to find out what help you need and then signpost you to where you can get this help whether it be from the local authority or an external agency. In Northern Ireland, the Health and Social Care Trust carries out the assessment.

Many people are put off by the idea of an assessment, but it's not something you should worry about. A social care assessment is not a test you can pass or fail. Instead, it's a straightforward way of working out your individual care and support needs, so that your local authority or NHS trust can decide the best way to help you.

The 2014 Care Act sets out the process the assessment must follow and the minimum threshold of need that the local authority should support.

It allows you to take the lead in explaining what care and support you need to make life easier for you.

The Care Act states that your wellbeing and your wishes must be considered in the assessment process.

For example, you might want to stay in your home, and this must be taken into consideration. Or, if in the past your care needs have prevented you from joining in activities outside the home, but this is something that you want to do, this must be considered as part of the assessment and care plan process.

## Am I eligible for a care needs assessment?

You're entitled to have a care needs assessment no matter how much income or savings you have, and it doesn't matter how complex or simple your needs are.

If you care for someone, you're also entitled to a carer's assessment.

## How do I get a care needs assessment?

Contact the adult social services department of your local council and ask for one. Explain you need some help at home

and ask for a care needs assessment (also known as a social care assessment). If you don't know who your local council is, then this link will help you:

<https://www.gov.uk/find-local-council>

## Urgent assessments

If they believe that you need support urgently then, in some cases, a local authority can begin providing services before a care needs assessment has been carried out. A full assessment will take place as soon as possible to make sure the right support is in place.

## What happens at the care needs assessment?

A care specialist will carry out the assessment on behalf of the local authority or NHS trust.

You will be assessed either by a social worker (often called a care manager) or an occupational therapist (OT), depending on your level of needs. The person who assesses you should look at the following things in their assessment:





- ❖ The emotional and social side of your life.
- ❖ Your skills and abilities.
- ❖ Your views, religious and cultural background and support network.
- ❖ Any physical difficulties you may experience or any risks.
- ❖ Any health or housing requirements.
- ❖ Your needs and wishes.
- ❖ What you would like to happen.
- ❖ If you have a carer what their needs and opinions are.

Under the Care Act, the local authority must act to maximise your wellbeing and seek to prevent, reduce and delay any future needs. The assessor will also contact any other health and social care professionals who need to be involved in your assessment and care. They need to establish how many care outcomes you are unable to achieve in order to work out whether you are eligible for support. The Care Act 2014 imposed a general duty on local authorities to fully consider a person's wellbeing when assessing and providing care and support services.

It's a good idea to take a friend or family member with you to the assessment so that they can help you to explain how your condition affects you. If there isn't anyone who could go with you and you would find it very difficult to understand the assessment or to explain your needs, the local authority must arrange for an independent advocate to help you at the assessment.

## What happens after the care needs assessment?

After the assessment, your local authority or NHS trust will decide what care services it can provide or arrange for you, or that you can organise yourself through a direct payment from the local authority. This decision is made by comparing your care needs with a set of nationally agreed criteria which all local authorities must use. The assessor must also take into account how these needs affect your general wellbeing when they decide if you need support.

You can find out about the eligibility criteria on your local authority's website.

## Agreeing a local authority care package

Detailed information about the care services you need will be included in your care plan, which you will get a written copy of.

Care services can include:

- ❖ Residential care or nursing homes.
- ❖ Disability equipment and adaptations

to your home – such as grab rails, stair lifts or ramps.

- ❖ Home care help with things like cleaning, meals and shopping.
- ❖ Day care for your child if either you, or they, have a disability.
- ❖ Day centres to give you, or the person who cares for you, a break.
- ❖ A 'careline' phone system so that you can call for help in an emergency.

## Reviewing your care and support plan

Once your care and support plan has been agreed, you have a right to ask for a review at any time if you think your care needs or your financial situation has changed.

Even if nothing has changed, the local authority must review it regularly, usually once a year.

## What if you move outside your local area?

If you move outside your local area, both local authorities must work together to make sure that you will still receive the support you need in your new home.

It is up to you to let the new local authority know that you're moving into their area so they can get a copy of your needs assessment and care and support plan.

If you have a carer the local authority in the new area must support them too, if they are coming with you.

## If you don't qualify for local authority support with care

If your local authority thinks that you don't qualify for support because your care needs aren't great enough, they must still give you information and advice about where else you can get help – for example, through charities or other local organisations. This information must be tailored to your needs.

If you don't agree with the outcome of the care needs assessment, your first step is to ask your local authority for a full written explanation of their assessment and how they came to their decision. If you're still unhappy after reading their explanation, contact your local authority and explain why you think their decision is unfair.

Every social services department has a complaints procedure, and must tell you how to use it.

## Paying for care – the financial assessment or means test

Once your local authority or trust has worked out what care services you need, they'll carry out a financial assessment. This is called a 'means test'. This will work out if you need to contribute towards the cost of your care, and whether the local authority will pay for all or some of your care costs.

If you need care to stay in your own home the means test won't include the value of your property. If you need to move permanently into a care home, the test will usually include the value of your property. Certain types of income, such as money from certain disability benefits and pensions, may not be counted in the means test. All other income can be taken into account. In some cases, the local authority may also assume that your capital generates an income, which will also be taken into account. If you and someone else jointly hold capital, such as a savings account, it will be treated as divided equally between the two of you.

It's also very important to ensure that you get all of your benefits and entitlements. This is because the means test will assume that you are receiving all the benefits you are entitled to, even if you aren't already claiming them.

Your local authority will only pay for community care services and can't provide nursing care.

## What to do if you're unhappy about the results of your assessment

If you or someone you are looking after if you're a carer wants to complain about a decision made by social services, you can use the statutory complaints system. If you want to complain about your local authority, you should do so in writing or verbally to the complaints manager within 12 months. They should acknowledge your complaint within three working days. They will also inform you of how long your complaint is likely to take to investigate. The local authority must respond fully within six months, unless a different time period has been discussed and agreed with you.

If you are not satisfied with the response you receive from your local authority, you are entitled to ask the independent Local Government Ombudsman (LGO) to investigate. The Ombudsman can investigate complaints about local councils. Further information is available by calling 0300 061 0614 or online at [www.lgo.org.uk](http://www.lgo.org.uk) ■

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# Looking forwards

ton  
shrewsbury

**I am running the Gateshead 10K in July. As well as helping to raise awareness and remove the stigma of having an ostomy I know that Colostomy UK will be able to use the funds I raise to continue offering help and support to ostomates across the UK.**

I use the hashtag **#lookingforwardsnotbackwards** on everything I do, as this is a reminder to me of how far I have come since my diagnosis. It keeps me focused on moving forwards and when you read my story I hope you'll see why.

In April 2015, I was suffering from bad abdominal cramps, I felt sick and I was getting uncontrollable rigors. I could not get an appointment with my GP and was advised that as I was in pain I should go to my local A&E Department.

Initially, I thought I had a tummy bug, but what happened next changed my life forever. I went to A&E and I was seen almost straight away (I know...I as was surprised as you are!). I went through my symptoms and had bloods taken. My blood pressure was found to be through the roof. The results came back showing an infection in my blood and, as I was in so much pain, they gave me morphine and I was admitted. Later that evening I was visited by a surgeon and his consultant. They arranged for me to have an MRI scan where I was injected with some dye. When I got back to the ward the surgeon was already waiting for me. He advised me that I needed an operation immediately as I had a perforated bowel. Next thing I knew I was being wheeled down to theatre, into the anaesthetic room and then sent off to the land of Morpheus.

The next thing I remember was somebody saying: "Ian, Ian, Ian can you open your eyes for me?". I was being woken up by a nurse. The room was pitch black with some lights dotted about. I was in intensive care and it was two days after my operation. I looked down and I could see that my laparotomy scar was covered. Then I looked slightly to my right and saw what I can only describe as something looking like a bright red 'wine gum'. It was my stoma. At that point I got scared as everything had happened so quickly since being admitted and now it was real.

I was eventually moved to a ward. I was bombarded with information about stomas and colostomies. I had tubes and drains in virtually every orifice and I was linked to a machine giving me constant pain relief. Just as I was starting to settle down my consultant came to see me, then came the news...I had bowel cancer! They had had to remove a large part of my intestine, leaving me with a permanent ileostomy. In addition, I was told that I would have to have radiotherapy.

It took me a long time to come to terms with my diagnosis and used to my new toilet habits. I became very depressed, especially during the radiotherapy. My stoma, named 'Thera' (after the Greek volcano) had a mind of its own. I had leakages often and needed to change my appliance a lot.

I am glad to say that I now feel a lot more confident and better in myself, although I am still self-conscious of leaking and ballooning. I am also surprised at how others feel about me having an ostomy. Believe me when I say true friends and family stick with you through everything. My parents and siblings live nearly 200 miles away and I have received no support from them at all and they've stopped all contact with me. Their loss not mine! On the other hand I have some truly amazing friends who have supported me through my journey and I am constantly making new friends through **Colostomy UK**.

If you would like to sponsor Ian visit his Just Giving page at: <https://www.justgiving.com/fundraising/ian-condon>.

**Ian Condon**



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# 50K

## CHALLENGE

It has been three months since we launched the 50K challenge and the response has been phenomenal. Hundreds of you have signed up to take part and are walking, cycling and running across the country. You are all doing your bit to raise awareness too and fight the stoma stigma. Thank you to everyone taking part and to those of you raising funds for us at the same time. At the time of going to press you have completed 15,000km towards our 50,000km target and raised over £6,000. If you have not yet signed up, perhaps the following stories will inspire you? The challenge runs to the end of October, so there is still time. To find out more visit [our website](#) or call us on 0118 939 1537.



### Brian's story

I had my colostomy formed in December 2005 as a result of cancer. Surgery was followed by chemotherapy. I spent 2007 recovering and then purchased my first bike the year after. In 2012 I cycled to Heidelberg and every year since I've taken the bike to Europe. As I write these words, I am halfway on a ride to Munich. This started in Belton (Rutland). My first stop was in Hull where I picked up the ferry to Zeebrugge. Since then I have ridden through Belgium, Holland and Germany, seeing the Rhine and the Danube and experiencing all sorts of weather! By the time *Tidings* hits people's doormats I will be at the Polish border and will have completed more than 50K km since I got in the saddle back in 2008.

FREEPHONE HELPLINE: 0800 328 4257



### Laura's story

Laura (above) I was diagnosed with stage 4 bladder cancer in September 2017, with first symptoms only in August 2017. I had a total pelvic exenteration on 1 November 2017 which was a 12-hour operation to remove my bladder, part of my bowel and all my other female reproductive and pelvic organs. This resulted in me having a permanent colostomy and urostomy created. Before this I knew nothing about what a stoma was. **Colostomy UK** has helped me lots with awareness and the practicalities of living with two stomas. I am taking part in their 50K challenge to continue my improvement of my fitness level and to raise awareness.



### Julia's story

My personal best time for running 5K (in recent years!) is 31 minutes and 40 seconds. I equalled this time three days before I had major surgery for bowel cancer on 30 January 2018. The surgery resulted in a permanent colostomy and subsequently I started six months of chemotherapy treatment on 19 March.

My aim is to gradually and gently get back to running and beat my 5K personal best by the end of October this year, whilst raising money for **Colostomy UK**. Training will have to be slow and gentle to begin with and training opportunities will be limited due to my chemo treatment regime, however any money I raise for **Colostomy UK** I'm sure will spur me on to achieve my goal. In the past few months I have received wonderful support and information from **Colostomy UK**, helping me get accustomed to my new life with a stoma, so I want to use this opportunity to give a little back.

I will also be logging all training kms towards **Colostomy UK's** 50K challenge.

# Dear Nurse

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



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

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

**Q:** *I had my colostomy in 2012 due to diverticulitis and a perforated gut. It was treated with antibiotics but I got peritonitis so I was given an emergency colostomy. I have irrigated for the last five years very successfully, but over Christmas I had the very bad cough that was going around everywhere and I got a chest infection, which was treated with antibiotics. The cough made my hernia a lot worse, and also I got very bad backache. I have not had trouble with my back before, however I now have really bad backache and my hernia is painful which it wasn't before.*

*The doctor has put me on maximum painkillers – codeine and paracetamol and I also have a patch. This is not dealing with the pain sufficiently and I'm going to see my doctor on Monday to enquire about having a steroid injection. I have seen the doctor five times to try and get everything sorted*

*out and had an x-ray for my back. I have phoned the stoma nurse and seen her for help.*

*My problem is I can't balance the laxatives with codeine I am taking and I'm either passing rocks which is very painful or I pancake and have to change my bag many times a day. This has never been a problem before. I haven't been able to irrigate since Christmas because the hernia now seems to be stopping the water going in. Also my energy levels have dropped considerably which I think is because of the pain. I have tried using Laxido, Fybogel, Senna and Lactulose, however I can't seem to get the right combination to deal with cause correctly, which is the high codeine intake, I need to control the pain. Which it isn't doing very well. I have been advised to take the Fybogel in the morning and the Lactulose in the*

*evening. I can't seem to get the timing right as if I've got diarrhoea I am reluctant to keep taking the laxatives but I don't know how long the cycle is. How long does it take for it to go from very painfully hard to normal?*

*I do hope you've got some information that will help me. PS I am 86.*

**GR**

**A:** Balancing pain relief and laxatives to keep the bowel functioning in a satisfactory manner is often difficult. Obviously you need to take the pain relief to ensure your pain is well controlled. To try to maintain a good bowel action you need to ensure you are drinking plenty of fluids, about 2 litres per day is ideal as well as ensuring you are eating healthily including fruit and vegetables. With regards to the laxatives it is difficult to advise as everyone is different. Maybe start with



taking a Fybogel every morning and every evening to try to soften but form your output. If after a few days this is not helping to regulate your bowel action you can try to add in other laxatives such as Lactulose, Senna, Movicol but do this gradually so that you can see what works. If possible it might be useful to have regular telephone calls to your stoma care nurse so that they can help to monitor and advise with regards to the laxatives to try to manage this problem. Once you have identified the system that works for you, you can then just contact the stoma care team intermittently if further problems occur. I hope this helps and that you get your pain under control as well as ensuring the bowel functions well.

**Q:** *I wrote to you about a year ago when my wife was finding it hard to position a bag due to a prolapse. Since then she has developed psoriasis around the stoma area. A steroid cream was prescribed but it is preventing the stoma pouch adhering, even after allowing the cream to dry and applying powder to the area. Could you offer advice regarding this problem?*

**RFA**

**A:** Treating a skin condition such as psoriasis is often done by a dermatologist and it is useful if this can be done in conjunction with the stoma care team as cream based treatments often do prevent the pouch from adhering. There are other gel based treatments that can be used which the pouches will often adhere to better. I would suggest a review with the doctor who is treating your psoriasis and ask if the stoma care nurse can be available for the appointment so that a joint review of the skin problem can be undertaken. This will hopefully enable a treatment plan to be devised which not only improves the psoriasis but also manages the stoma appropriately.

**Q:** *I found your article very helpful. I am 94 years old and have had a colostomy (loop) since June. In December I had a prolapse which alarmed me as I knew*

*nothing about this happening! Eventually I went to hospital where the surgeon pushed it back! This week a small appearance of 'something' which I pressed and so far all is well but is it alright to try and push it back? Any help gratefully received.*

**YS**

**A:** A stoma prolapse is when the bowel protrudes further than is usual. As long as the bowel remains healthy and is acting the prolapse can often be managed without the need for surgery. I would advise a review by your stoma care nurse to check that the prolapse is not likely to cause a problem with pouch adhesion or the stoma itself. The template needs to be checked so that it fits correctly around the stoma without causing any traumatic damage to the bowel tissue and does not leak which can cause skin problems. Even if a stomal prolapse is able to be pushed back it will often reoccur and often a support belt may help with this, again your stoma care nurse can advise.

**Q:** *I have had a colostomy for over 10 years due to a lack of blood which followed emergency surgery for a ruptured abdominal aortic aneurysm (Triple A). I am very aware of the efforts made to save my life and can only thank the fantastic surgeon and medical team who worked tirelessly on me for many hours. For a few years afterwards I attended a stoma clinic which I found very helpful. However, I have only seen a stoma nurse on an irregular basis for some years and I am sure this is due to the volume of work they have. My stoma has never settled down and the output is very erratic and it is difficult to make plans for days out and holidays. I watch what food I eat and have tried to establish if this is normal and if I can do anything to help and make my life easier! I am now 77 years of age and prior to the Triple A was in reasonable health (apart from Diabetes type 2, Glaucoma, Heart Attack 1981) and I am still active but somewhat slowing down. My question is:- should I see a Stoma Nurse on a regular basis i.e. once a year, twice a*

*year or not at all? I am also aware that the medication that I take can have an effect on my condition.*

**Name withheld**

**A:** Different stoma care teams have differing follow up protocols. Within my own team we see patients regularly immediately following surgery until approximately 3 months after stoma formation. After this patients are advised to telephone us for advice and, if needed to be seen in clinic, we ask for a GP referral. We also do annual telephone calls to our patients so that we can identify any issues and again see them in clinic if necessary. If you are having problems I would certainly advise a review by your stoma care team, they will not know you are having problems unless you contact them. You can also ask them what their usual follow up protocol is so that you can ensure you are being contacted or seen as needed. ■

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

E-mail:  
**editor@ColostomyUK.org**

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

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

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



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# Readers' Writes

## Your letters and emails

### Dear Editor

Due to problems in childbirth and having some further surgery, I began experiencing bowel difficulties. Later I had surgery to repair my sphincter in 1999. This was followed by having a temporary colostomy formed. Unluckily I got a hernia round this area. Later in 2002 I became unwell with lots of problems, I went into St Marks Hospital for further surgery for an end colostomy, with the temporary one repaired and closed. This was my first visit to St Marks and as the years have gone by I have returned for other procedures.

At the present time I am having trouble with my stoma going concave. As well as discomfort and pain my stoma also sometimes stops working a little. I feel very worried and apprehensive. I am getting medical advice and support from **Colostomy UK** and my GP which I appreciate and I may require a further hospital visit. If possible would you be able to do an article on concave stomas so it will hopefully give more of an insight into this problem for myself and anyone else who has these concave issues. **LDS**

*Retracted stomas can be a problem to manage and we did write about them, along with prolapsed stomas in 2015. We would be very happy to send the previous article to you but will also look at visiting the subject again in the near future as this is an issue which many of our readers report as being troublesome.*

### Dear Editor

I attach notes on how I cope with ballooning. I am sure you must have come across others who have found similar solutions to the problem but I have never

seen it described in written instructions. It would seem the experts on these matters frown upon its use and I wonder why. **HJB**

### A DIY method of dealing with ballooning

I am 94 years old and eight years ago my wife and I had over 60 years of married life. She had a pacemaker and I had an irregular heart and was on warfarin but we were both fairly fit. Then, out of the blue, I developed a twisted gut and had to have an operation quick. It took a few days to reduce the warfarin in my blood and then I had a colostomy and finished up with a stoma. After five weeks in hospital, I had lost nearly two stone and I went home to the loving care of my wife and family. In a remarkably short time I began to get my strength back and feel better. One of the problems I experienced was ballooning and under the care of my stoma nurses I tried all the recognised methods. I experimented with my diet and was amazed at all the foods that give you wind. I bought some plastic valves that were available at that time but they could only be used once and I did not like them. I was not happy with any of the prescribed methods and decided to experiment to find a better method and came up with the following:

1. Using a sealed pouch I pull back the material on the outside exposing the plastic pouch beneath where I can see the round hole of the pouch exit. Using this as a target I stick a white patch provided with the pouches, right in the middle then I pull back the covering and use in the normal way.
2. If I get ballooning then I again pull back the cover and, using the small sharp scissors provided to cut the right aperture in the bags, I push the scissor point into the centre of the patch making a small

triangular hole with a little flap which releases the gas instantly. I wipe off anything that has come through and put a new patch on top to seal the hole. In my case I developed a small hernia and I wear a belt with a hole in it that the pouch passes through but this does not hinder the process. I also have to take half a sachet of a mild laxative every day to keep the pouch contents soft. Sometimes when the inside wall of the pouch behind the patch is covered with contents, I squeeze the patch and pouch between my thumb and finger and in this way I make sure that the scissor point goes into a space to release the gas.

3. If after a while the pouch balloons again I repeat the process but this time I will be making the hole through two patches and pouch. This process can be repeated several times and I sometimes have four or five patches one on top of the other

**Conclusion:** The method is simple, efficient and reliable. I have used it for many years and never had a patch that leaked.

It is very quick – only a couple of minutes.

There is no mess only a smell as the gas releases.

You can eat what you like and not worry about ballooning.

It gives you confidence that you have ballooning under control ■

*Thank you so much for writing in. We would always recommend you see your stoma nurse if you are having issues such as this, as a change in bag may help, but sometimes a novel method for managing a common problem can make all the difference to another ostomate who is suffering.*



### Your magazine – Your story

**We want to hear from you.**

Letters and e-mails to the editor are welcome, but we also want your stories and anecdotes. Perhaps something in *Tidings* has inspired you? Or maybe you've noticed something that has a bearing on one of campaigns or projects? And then there's hints and tips for ostomates, we want to hear these too...and so do our readers. Don't worry if writing isn't your thing, because we can do this with you. So don't delay, drop us a line, send us an e-mail, or give us a call and we will take it from there.

Email to: **editor@ColostomyUK.org** or write to: **The Editor, Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA.**

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v

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Contact:

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# New products and services

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

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# Jane Bland reveals

**I had an exciting time in January...doing a naked photo shoot for *Good Housekeeping* magazine! It all followed Colostomy UK's request on their Facebook group for women with good body confidence. Thirty years after being diagnosed (at age 28) with body dysmorphia, this is me; I'm now very comfortable in my skin. I submitted my story, was interviewed on the phone, sent in some photos and then, lo and behold, was selected as one of four women to face the cameras! I went by train to London from my home in Newcastle-upon-Tyne and stayed in a nice hotel overnight as I had to be at the shoot for 9am the next day. Cars picked me up for every journey. I felt like a pop star.**

**On arriving at the shoot no time was wasted...I was immediately asked to go behind a screen and remove my clothes and put on a robe. I was like: "Hello, good morning" – but was told this was so I would have no visible sock, knickers or bra marks! The folk from the magazine were brilliant and so welcoming. I had fun chatting to them all while my hair and makeup were done. By the time it came to remove the robe I was feeling less nervous and more relaxed.**

The photographer positioned me and click, click, click went her camera. She and the staff checked the pictures as we went along. My make-up was touched up as required and more pictures were taken and so on. I guess I was naked for about an hour with them stopping to check the photographs. It's a surreal experience to sit on a stool naked when people are looking at your pictures and you are ignored!

When I got dressed, I was interviewed again and asked how I felt having done it. Although my instant reaction was negative, this was fleeting. Within moments I realised that it was an enlightening and empowering experience. When I looked again, I saw a confident lady despite the scars and stoma bag. One brilliant thing to learn was that I wasn't bothered at all about my bag being out. I couldn't have imagined that four years ago. The male photography assistant said I shrieked of femininity. He was right, on looking again I could confidently say 'I was all woman'. It was a brilliant thing to do for my self-esteem, especially when the Features Editor told me a lot of women had applied to do it but only four of us had been chosen.

The subsequent article in the May edition of *Good Housekeeping* focuses a lot on my tattoos. I hated how my body was being scarred and altered by scars through two cancer operations, and then the three



# Is all...



colostomy operations. Tattoos were my decision to scar my body in a way of my choosing and they are delicate and pretty. I do find it unbelievable now that I once hid my body away behind dark baggy clothing and wouldn't have a full length mirror at home. I wish I could have felt then as I do now. Of course my body isn't perfect in any way but it works for me!

The other three women were also a pleasure to meet. I hope that they too have received as much positive feedback as I have. It's very humbling to be referred to as 'inspirational' or a 'hero' just because I had a photo taken! The photoshoot and the kind messages that followed have really boosted my self-confidence.

So my message to anyone reading this is get out there people and stop worrying about what your body looks like, don't wait like I did!

**Jane Bland**



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## Irrigation



Sarah Squire – Trustee and Co-Editor

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

## Irrigation: is it worth it?

### Patrick writes:

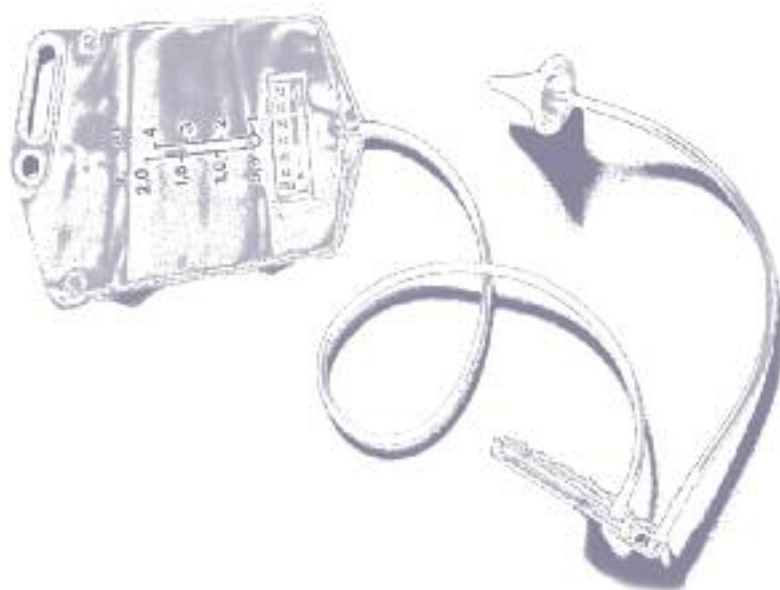
**At first glance my overwhelming feeling was no. All that faffing about with water and cones and tubes didn't seem for me. But, having taken a closer look and actually trying it, I now feel completely differently.**

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# ion and You



My name is Patrick Reeve and at the age of 47 I was diagnosed with bowel cancer. As my tumour was very low in my rectum, my consultant said that he would have to remove the rectum and anus, leaving me with a permanent stoma. Not the news I was hoping to hear, but it was better than the alternative! So, in September 2016, my stoma was formed. I named him Cecil and, up until three weeks ago, I used a colostomy bag and changed it when required. Although I'm fortunate in that my bowel habits are quite regular (and so I had a pretty good idea of when I would need to change my bag) there was still that element of unpredictability. In the 18 months that Cecil has been with me I have had a couple of accidents, nothing too horrific but unpleasant, nevertheless.

I work as a mortgage broker and so I am often away visiting clients in their homes and near other people's toilets. Although I never had to change my bag whilst with a client, I knew it was something that could always happen. Likewise I often travel great distances to see clients. Having a two-hour car journey wondering if you are going to need to find motorway services is OK but, again, it's not something you would do given the choice.

## This is where irrigation comes in!

### So, what is it?

Irrigation is a method of emptying the bowel when you want to, rather than leaving it to chance. In the morning, I feed 1.5 litres of tepid water into my bowel via a cone that fits into my stoma. This is gravity fed via a container that you hang up at head

height. It is not painful and you quickly become used to it. If you feed the water in too quickly all that happens is it comes straight back out again without bringing anything with it. However, introducing the water more slowly encourages the bowel to eject the water and with it its contents too. The process of infusing water takes me about twenty minutes, with stops along the way if the bowel needs to eject. I stand when I irrigate but some people sit on the toilet or in a chair. For me, standing means that everything feels like it can work better, but it's personal choice. Once all of the water is in, it takes about another twenty minutes for my bowel to finish ejecting the water. After about 10 minutes, it is possible to clip the end of the bag up so that you can move away from the toilet safely. As I irrigate in the mornings, I use the time (once I can move away from the toilet) to shave, clean my teeth etc, so that the time impact is not too great. So that the poo goes into the toilet and not everywhere else, you wear a sleeve over your stoma. In effect this is a long, soft, plastic sleeve with a flange exactly the same as a colostomy bag. The end of the sleeve then goes into the toilet so that it all goes into the right place!

When I am happy that we are all done – you can feel when it is coming to an end – I remove the sleeve and shower. It is good to be able to shower without a bag as it gives the skin around your stoma a chance to 'breathe', instead of having a bag stuck to it all of the time. Once I have showered I put on a stoma cap, rather than a colostomy bag; the bowel will not eject any further contents as it should now be empty. I feel this is a great advantage as it means the bag is less visible (as it is much smaller) and I don't have to be so conscious of the

bag poking out of the bottom of tee shirts, for example. Before, I always wore my bag 'outside' of my trousers if I was wearing a tee shirt as I found that tucking the bag in made it show more under a shirt. I wear a suit whilst I am at work and again, the cap is less visible. However, the main advantage of irrigation is it gives back predictability! I can go out for the entire day now and not have to worry about whether I have 'been', whether I am about to go, or be on the lookout for the nearest toilet, just in case. If we were eating out, I would always be concerned that soon after I had eaten my stoma would start to work and, although it never stopped me doing anything, there is always that 'what if?' With irrigation this has all stopped.

At the moment I am still irrigating every day but will be moving to every other day soon. Some people I am told, irrigate every third day. All the supplies you require are provided by the stoma nurse. You re-order them just as you would your other stoma supplies. I have also purchased a small hook that I place over the top of the shower screen in the bathroom. This will also come in handy when we are on holiday as it means that I can continue to irrigate whilst we are away.

## How do you start?

All it took was a call to my stoma nurse. She arranged to visit me at home with a colleague to show me the ropes. I think at times my wife, who was downstairs, must have wondered what on earth was going on, with three of us in the toilet and me just in my underwear! There was much 'ooohing' and 'aahrring' as the bowel started to eject its contents. "That's the best one we've ever

CONTINUED ON PAGE 33, COLUMN 1

### Photo ID Card

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

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

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

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

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## Colostomy Irrigation and You DVD

### Order Form Colostomy Irrigation and You (Patients)

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

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

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

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CONTINUED FROM PAGE 31, COLUMN 3

done", I was told. I was congratulated – but really it was all down to my bowel, I was just a bystander! A few days later, my stoma nurse called to see how I was getting on and said that she went straight back to her office after showing me how to irrigate and told all her colleagues about me, fame indeed!

At first, like all things I suppose, irrigation looks complicated. But, once you have been shown what to do and learn to do it your way, it is really very simple. Now, just like when I had my colostomy bag, irrigation is part of my daily routine. I have to get up 30 minutes earlier than I did before but the payoff is that once I have finished in the bathroom I don't need to worry again until the following morning or, the morning after, when I begin to irrigate every other day. And, at bedtime, I don't have to put a clean bag on, which has cut down the amount of time I have to spend in the bathroom before bed. Sometimes, you just want to go to bed and not have the hassle of changing a colostomy bag. Every night now feels like a treat when I can just clean my teeth and go to bed!

To say that irrigation is liberating may be overstating its impact, but it really is a relief

to be able to go about your day without constant thoughts of 'the bag'. Notwithstanding all of that, I still make sure that I have supplies with me, whenever I go out. So far, since I have been irrigating I have not 'been' during the day, but I still think it prudent to have supplies to hand.

The last advantage that I think is worth mentioning is wind! We've all been there, in a quiet room, full of strangers, when your stoma decides that now would be the perfect time to expel the noisiest wind you have ever heard! Because irrigation empties the bowel, there is less wind, which cannot be a bad thing, right?

I would say, if you are considering irrigation, please give it a try. If you don't get on with it or you just decide that you don't have time, you can go back to a colostomy bag anytime you want. I am sure that once you have had a few days of predictability, you won't look back. And, there is a large range of stoma caps that you can try, some just look like plasters and so are really discreet.

Good luck and I hope that you give it a try.

For details of my complete cancer 'journey' take a look at my blog at:

<https://http2279.wordpress.com>

Patrick Reeve

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

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

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# The Conseal plug – an option for the colostomate

**This feature provides an overview of the Conseal one-piece Plug and answers frequently asked questions.**

**The Assura® Conseal Plug can be used by colostomates who have a colostomy and produce a regular soft formed stool.**

The single-use plug is very easy to use, enabling individuals to have periods during the day where they replace their usual bag/pouch with this small discreet plug. This may be as part of their daily stoma management routine or for shorter periods during activities such as swimming offering a greater feeling of discretion, control and confidence.

The Conseal plug may not be right for everyone, it is a matter of choice and should always be discussed with your local stoma nurse prior to using. **Please note: the plug is not suitable for people with an ileostomy or urostomy.**

*"I use the Conseal plug during the day, I am a busy grandma who babysits regularly for my grandchildren. The plug gives me freedom from the bag and confidence during the day when I am with them. It allows me to be active with them without the worry of having to look after my Colostomy bag". Mrs A*

## What is the Conseal plug?

The Conseal plug has a lubricated soft foam stalk which is attached to an adhesive skin barrier (flange), shown in figure 1.

The stalk of the plug acts like a 'bung' when inserted into your colostomy. Once inserted, the coating on the stalk breaks down when it meets the moist lining of the bowel, so that it can expand (much like a tampon) and prevent faeces from leaving the bowel. You can see this difference in the stalks in figure 1.

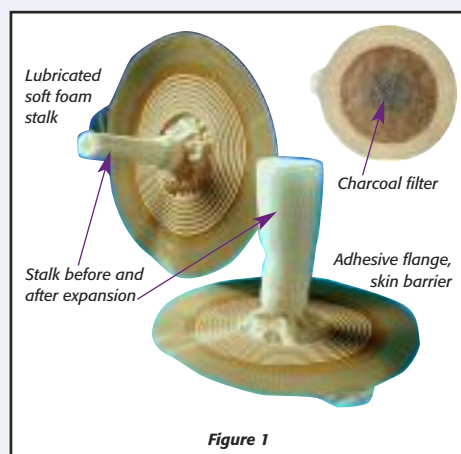


Figure 1

On the outside of the plug, there is a charcoal filter (figure 1, top right) which allows gas/wind to be expelled preventing noise or odour.

The spiral adhesive (sticky) flange (skin barrier) (as shown in figure 1) has been specifically designed to provide a secure, flexible adhesion that is skin friendly. This ensures your skin remains comfortable and healthy while being flexible enough to adapt to the movement of your body.

## Who can use the Conseal plug?

The Conseal plug is preferable for colostomates with an 'end' colostomy that produces a regular, soft-formed stool. If you are unsure of the type of stoma you have – you should contact your stoma nurse and discuss this prior to using the Conseal plug.

Due to the adhesive flange size of the Conseal plug you would need to have a stoma size of less than 45mm, as the cutting zone on the back of the flange can't be cut any larger than this.

## How long can the Conseal plug be worn?

**1–12 hours.**

Although the Conseal plug can be worn for between 1–12hrs; your normal bowel pattern/activity will dictate how long it can be worn.

The Conseal plug should ideally be inserted into your colostomy after a normal motion has been passed into your stoma pouch. The plug should be removed when it is anticipated the bowel needs emptying or

you have a feeling of fullness, which means the stoma needs to work. People with a colostomy who have a regular (bowel) movement, or use colostomy irrigation may use the Conseal plug for up to 12 hours. For others, the plug would only be worn for the period during their chosen activity such as swimming, sports, dancing or intimate moments.

When the Conseal plug is first tried, some people find a period of training is beneficial to give their bowel time to adapt to using the plug. For some this may be a matter of days – for others it may take a little longer two–four weeks. After the initial training period, the Conseal plug can be worn for as long as you find it comfortable and dependent on how active your bowel is.

## Can I use the same Conseal plug on more than one occasion?

**No.**

The Conseal plug is designed for single use only. Washing, disinfection or sterilisation of the plug may compromise the materials it has been made with; this could cause physical harm to the stoma or infection to the individual using the plug.

## Do you have to wear the Conseal plug regularly?

**No.**

The plug can be worn occasionally. Many people wear the plug for short periods only (as noted earlier) or when wearing certain clothing and wishing to achieve a greater feeling of discretion.



1. Remove Plug from packaging.



2. Remove protective backing from adhesive flange.





## Do you have to irrigate to use the Conseal plug?

**No.**

However, if you do irrigate this is an option for you and you may wish to wear the plug in between irrigations.

## Will the Conseal plug ever pop out or be ejected from the stoma?

**No.**

The plug will not just pop out. The adhesive flange will keep it securely attached to the area around your stoma. However, during the training period, the plug can be pushed out of your stoma (under the flange) simply because your bowel is not used to the plug (this is because of contraction of the bowel against something new being inserted). As you relax and get used to the plug this will usually stop happening. If this does happen to you, remove the plug and re-insert another one.

## Will there be rapid evacuation of faeces when I remove the Conseal plug?

**No.**

Once the plug has been removed, there will be time to change to your normal pouch before the faeces will start to come out of your colostomy. Just plan to have your products ready as you would do for a routine bag change/irrigation.

## Can the Conseal plug cause constipation?

**No.**

During the training period a few people have experienced constipation, however as the bowel gets used to the plug this will settle back to your normal pattern. If you do experience constipation at any time, use your regular pouch until your output returns to normal again and then go back to trialling the Conseal plug. Try to follow a healthy, well balanced diet with plenty of drinking water to reduce the risk of constipation.

## What should I do if I have diarrhoea?

A Conseal plug should not be used if you are experiencing diarrhoea. If diarrhoea occurs suddenly, remove the plug and wear your normal or a drainable pouch. Once you are back to your normal regular bowel pattern you can restart using the plug.

## Will the Conseal plug leak?

If you experience unexpected diarrhoea, there may be a possibility of leakage under the flange or through the filter (please see above question related to diarrhoea). During the initial training period, a few people have reported some faecal leakage underneath the flange, however this has stopped once the bowel has got used to the Conseal plug. If you do experience a leak, it is worth considering if you have an unpredictable bowel pattern and left the plug in for too long. If you have any concerns about this, please discuss with your stoma nurse.

## Can the Conseal plug cause any irritation or discomfort to the bowel?

During the training period, you may initially feel some slight irritation or discomfort within the bowel (because the bowel is getting used to the plug). If this is the case, the plug should be removed and the bowel rested for a day or two before a new Conseal plug is inserted and retried. Although the plug "stalk" is lubricated you can always add more lubricant gel and this may reduce irritation of the bowel wall.

Some colostomates have reported seeing flecks of blood on the stalk of the plug when they remove it from the stoma. Although surprising to see, this is not unusual, the bowel lining (mucosa) has a healthy blood supply and just like when you clean your stoma, you may see spots of blood on your cleaning tissue. There is no evidence to suggest the Conseal plug causes any long term trauma to your bowel and there have been no reported allergic reactions.

*"I regularly use Assura Conceal and think it is brilliant. I practice colostomy irrigation and am not sure I would use the plug if I didn't. If I am going to an event where I do not want embarrassment of 'noises' from my stoma I use a Conseal plug and it gives me 100% confidence. A marvellous invention."*

CB

## Will the Conseal plug give me more freedom?

**Yes.**

The Conseal plug is frequently reported to give greater freedom of movement. You may find it easier to do physical activities such as swimming, football, dancing etc. The plug is also a nice alternative for intimate moments.

*"I have been irrigating and using Conseal plugs for about seven years. I really like them as they fit comfortably and you can almost forget about it. They also stop any escape of wind which is really good."*

Mr DO

## How do I go about obtaining the Conseal plug?

The Conseal plug is available on prescription. It is advisable you speak to your stoma nurse to find out which size would be most suitable for your needs.

There are four sizes of Coloplast Conseal plug, and it is available as a one-piece product.

Coloplast advise to start off with the smaller 35mm Conseal plug as bowel adaptation time is dramatically reduced.

We hope this article has answered some of your questions about the Conseal plug. If you have any additional questions please contact Coloplast Care telephone line on 0800 783 1434, option 2. If you are interested in trying the Conseal plug please seek advice from your own stoma nurse.

**Wendy Osborne**

Stoma Nurse Specialist  
Clinical Lead – Coloplast Ltd



3. The plug is lubricated to allow easy insertion into the stoma.



4. Gently insert the plug into your stoma, ensuring the adhesive flange (skin barrier) fits around the stoma.



5. Press the adhesive flange to the skin and then gently place your hand on the centre of the flat cap for a few seconds to ensure adhered to your skin.

# Win up to £25,000 with Unity

**50p**  
from every £1 goes to  
**Colostomy UK**

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

## How it works

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

## How to join – three easy steps

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

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

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

If you have any queries please call our hotline on

**0370 050 9240**

Results & Rules can be checked by visiting

**www.unitylottery.co.uk**

Or by phoning the Unity winners hotline

**0370 055 2291**

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

## Prizes

**£25,000** 6 digits

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**£25** 4 digits

**5 Prize Entries** 3 digits  
in the next draw

### 1. Your details (please print in block capitals)

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

### 2. Payment Frequency

How many entries would you like each week?

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

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

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

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

Post this form in a stamped envelope to:

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

For office use only:

### 3. Select your Payment method

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

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



# Chlorine, the breakfast of champions



Richard Biddle – Writer and Researcher

**How many times have you been told that exercise is good for you? Depending on how you say it, this can sound like a simple question or a cross Mum nagging a child to go out and get some fresh air. Although I wouldn't want you to think of Colostomy UK as the latter, I'm not going to make any excuses for re-stating that there are both physical and mental benefits to being an active ostomate. And, just to clarify, when I say active I don't necessarily mean things like playing football or running marathons. A walk to shops or a potter in the garden counts too.**

Evidence of the benefits is plentiful. I could, for example, extract some choice comments from the Department of Health's report (2011) *Start Active, Stay Active*. One of the things it makes clear is that adults who engage in daily physical activity (whatever their age) are at a reduced risk of depression, distress and anxiety than those who lead sedentary lifestyles. I could also quote from more recent sources, such as last year's excellent article by Sarah Russell (ostomy health and well-being specialist) in the *British Journal of Nursing*. But, if you're like me, then you wouldn't find this more academic approach quite so inspiring as a 'real' human story. Hence my tact is slightly different. I'm going to tell you about the ostomate-only swimming sessions we recently organised and let one of those who attended tell you, in his own words, the immediate and lasting impact it has had on him and his young family.

Thanks to funding from the National Lottery, in March this year we were able to run two ostomate-only swimming sessions at Sheppey Leisure Centre in Sheerness. The idea followed Giovanni's (our Fundraising and Development Manager) visit to a meeting of Sheppey Ostomy Group Support (SOGS). This is run by Shelley Lawes who, if you do social media, will know is the lady behind the blog and Facebook page 'Stoma in a Teacup'. Rather than restrict the sessions to members of SOGS, it was decided to open them up to any ostomates and their families that wanted to attend. We all know just how daunting the prospect of swimming can be following stoma surgery. Indeed for some, the fear of bags leaking and people 'bag gazing' is enough to put them off altogether. Our hope, therefore, was that by offering a safe and supportive environment, we could tempt ostomates back into the pool and kick start their confidence swimming 'with the public'. With this in mind, there were no activities organised. Instead, everyone agreed that it was better just to let people do what they wanted and at a pace they felt comfortable with.

We had a wide range of ages attend and this included Matthew Banister and his family. Shortly after the session Matthew had the following to say:

*"I would like to thank Colostomy UK for hiring out the swimming pool and allowing me to go swimming in the company of my family and fellow ostomates. I have never been swimming with my boy and he is seven years old. When I looked back I realised I hadn't been swimming for 20 odd years. Ever since I received my stoma in 2003 I lost the confidence to go swimming. I always thought it would leak and I could not cope with the embarrassment. For my wife it was also a big step as she hasn't been swimming due to being image conscious. It has given us some great memories, seeing my little boy's face and seeing how good he can swim. I am still hesitant to go to a public pool, but I will go. The other good thing that come out of it is my wife now takes my little boy swimming and plans to do so regularly. Thank you to the Colostomy UK team for all the hard work you do and all the chances that you give people like me to have fun and make great memories."*

As I hope you can see, for the Banister family at least, attending the swimming session was successful in many different ways. Not only did it help to get Matthew in the water again, it also enabled the family to play together and create some memories that they will treasure forever. In this story, the physical and mental benefits of exercise are there for all to see. Like many people who undergo stoma surgery, Matthew started to wall off parts of his previous life; Sheppey triggered the process of breaking these walls down. I often feel that words like 'empowering' and 'empowerment' are over-used, but in this instance I believe their use is fully justified.

The swimming sessions in Sheppey were organised as part of our wider 'Active ostomates' project. So, if you are a member of a support group, and would like to explore ways in which Colostomy UK can assist in getting you and your fellow ostomates active then get in touch. And, please remember, this doesn't have to be swimming. It's about what works for your group. As you will have probably seen in previous editions of *Tidings*, we have helped support groups in various parts of the country to start everything from chair yoga to archery. ■

# Active ostomates



Giovanni Cinque – Fundraising and Development Manager

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

## In a league of our own

At **Colostomy UK** one of our key objectives is to spread awareness of what is still very much a misunderstood 'hidden condition', and to show that having a stoma need not be a barrier to being active and achieving anything you put your mind to.

What better way to do this than by starting up our own Rugby League Team? If we're going to use sport as a vehicle to showcase that people with a stoma can do anything, then why not use the toughest team sport out there!

Back in January through *Tidings* and social media we asked for people who were playing, or wanted to give Rugby League a go, to get in touch. The idea was to put our toe in the water and see what the interest levels were and whether it was an idea worth pursuing.

The response was positive enough for us to think that we might be able to get something off the ground. Indeed people from throughout the country got in touch and not just from the 'traditional' Rugby League playing areas. For every person from Leigh or Chorley we've also had people contact from Sidcup and Colchester.



Photo: Geoff Walsh

Due to the wide range of ages and Rugby League experience of those who've put their hand up to play, we have decided to start off by giving Masters Rugby League a go and not much more than six months after we first floated the idea, Team Colostomy UK Rugby League will make its debut against Medway Dragons Masters at Medway Park on July 21.

Masters is strictly a social version of the sport and the rules are slightly modified to cater for players of all ages and abilities.

SecuriCare and Welland Medical have come on board as partners which has allowed us to produce an eye catching kit that we launched at the London Broncos v Sheffield Eagles match on May 20.



It's been great for us to get to know a little bit about those that have signed up to play for us. It is also really encouraging to discover that there are already a number of people out there with a stoma playing Rugby League. They are shining examples of how having a hidden condition doesn't need to be an insurmountable barrier to living life how you want to.

Kav Ellison is 27 years old and plays for Chorley Panthers. In 2015 he had stoma surgery due to Ulcerative Colitis. In his own words:

*"I started playing rugby at high school and soon joined The Panthers. I represented Lancashire twice in my younger days and I've played roughly for about 14 years. I have been coaching for 3-4 years and got my level 2 coaching badge last year. I can honestly say that having a stoma hasn't had much impact on me actually playing rugby; it did though push me towards coaching a bit more."*

John Flood hails from Sidcup in Kent. His Team Colostomy UK debut will be his first ever game of Rugby League, although he has a background in Rugby Union. John last played Union in 2014 and since then has had 29 operations in four years.

This is John's story:

*"I've had ulcerative colitis since a very young age but it started getting worse around the age of 19 or 20. I was in and out of hospital in my late 20s and early 30s and unfortunately medication just wasn't helping anymore."*





## Stress Free Outdoors

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

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

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

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

*"In 2013 it was put to me that my best option was surgery. So in September 2013 I had my first operation (Total Proctocolectomy). Unfortunately, due to complications, this was just the start of a long period of hospital visits – which resulted in me having a permanent Ileostomy. Thankfully my operation last November was the 'final final' one and so far this has been the best I've felt in a long time. Unfortunately I thought this had put an end to my rugby career. Then I read about Team Colostomy UK, and I wanted to join this huge and exciting project, hoping it can spur me on to play again."*

The journeys Kav and John have faced post surgery have been very different, but what both stories highlight is that you can still achieve anything you put your mind to. The 17 men who will don the Team Colostomy UK shirt on July 21 are ample proof of this.

We are always on the lookout for new players so if you would like to join us please email [Giovanni.Cinque@ColostomyUK.org](mailto:Giovanni.Cinque@ColostomyUK.org)

To find out more about Team Colostomy UK Rugby League find us on twitter [@TeamColostomyUK](https://twitter.com/TeamColostomyUK) or call **0118 939 1537** or email [Giovanni.Cinque@ColostomyUK.org](mailto:Giovanni.Cinque@ColostomyUK.org)

## Fancy a dip?

After the success of our ostomate only swimming sessions in Sheppey earlier in the year we are looking for other opportunities for support groups to partner with us to host further swimming activities.

If you're interested please call us on **0118 939 1537** or email [Giovanni.Cinque@ColostomyUK.org](mailto:Giovanni.Cinque@ColostomyUK.org)



## Revised and updated Sport and fitness after stoma surgery booklet available

We have distributed over 6,000 copies of our *Active ostomates: sport and fitness after stoma surgery* booklet since its initial launch in 2016. The newly revised and updated version is now available which includes new sections on modified sports and updated advice and links to numerous activities you can try.

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

[info@ColostomyUK.org](mailto:info@ColostomyUK.org)

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



## Chair yoga

Support groups in Sheppey, Chatham, Cheshire, Stevenage, Dartford and Bracknell are amongst those who are taking part in our free chair yoga programme.

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

### Team Colostomy UK Baseball cap

£8.99

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100% soft touch acrylic. Embroidered  
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One size fits all.

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### Team Colostomy UK Beanie hat

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45% acrylic, 30% cotton,  
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Medium (38"/40")  
Large (42"/44")  
XX Large (50"/52")

Qty required: \_\_\_\_\_

Small \_\_\_\_\_

Medium \_\_\_\_\_

Large \_\_\_\_\_

XX Large \_\_\_\_\_



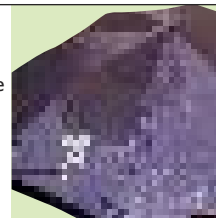
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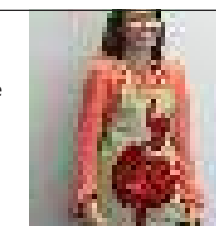
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Prolapsed stoma  
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Additional parts included in both models:  
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colostomy loop adaptor, ileal conduit.

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# I was worried that I couldn't have a family



Caption ??

After three miscarriages Jodie didn't think she would be able to have children. How wrong she was... now her two little ones are accompanying her on the **Colostomy UK 50K challenge**

**Jodie Hookway tells her story:**

I spent most of my teenage years unwell, with my illness misdiagnosed. Finally in 2003, when I was 18, I was diagnosed with Crohn's disease. I tried various medications and infusions to keep the disease under control, including azathioprine, methotrexate, Pentasa and other biologics. These worked for a while then I would relapse twice as bad. Then, in 2012, I was also diagnosed with perianal fistulating disease. This followed an MRI scan which also revealed that the complex perianal fistulation had caused numerous abscesses. These were treated using seton wires in areas that weren't very comfortable and required packing by district nurses.

CONTINUED ON PAGE 43, COLUMN 1

# Your travel checklist

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

The ostomate needs to remember to:

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

## Remember:

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



**General Enquiries:**  
0118 939 1537

**Monday to Thursday**  
9am – 5pm and  
**Friday** 9am – 3pm

or

**E-mail:**  
[info@ColostomyUK.org](mailto:info@ColostomyUK.org)

or download from our

**Website:**  
[www.ColostomyUK.org](http://www.ColostomyUK.org)



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CONTINUED FROM PAGE 41, COLUMN 3

From then on, everyday life became a struggle. Holidays were always plagued with an abscess or severe symptoms including bloating, which ruined any chance of fun. The simplest of things became hard work and making plans was pointless as I never knew how the disease would affect me from one day to the next. Thankfully, I wasn't alone. My family and, especially my Mum, were with me every step of the way, even though at times I must've been a nightmare to cope with.

Although I wanted to start a family, after three miscarriages I was ready to give up. But, with the help of a fertility doctor and simple blood thinning injections I conceived. In May 2013 I had Chad, my miracle baby, who made everything I had been through worthwhile. Unfortunately shortly afterwards my Crohn's flared again and in June 2014, when Chad had just turned one, I had a loop colostomy formed. The surgeon decided that by the faeces bypassing the rectum it would ease the perianal symptoms and buy me more time to extend my family in the future.

All was going great for a few years. I loved the freedom that the bag gave me. There was less pain, no abscesses and no running to the toilet. I had more control, which meant I was finally able to enjoy being a Mum to Chad. We got into a routine of me working and him going to nursery. We were living 'normal' life for a while. I still had Crohn's flare-ups, but these were managed with steroids and antibiotics alongside humira which, after receiving funding for it, I used to self-inject weekly. For me having a colostomy was the best decision I made, it allowed me to do anything.

Then unexpectedly, and without trying, I fell pregnant again. In April 2016 I had my beautiful daughter Ayda, again via c-section and after using the same blood thinning injections throughout the pregnancy. My family was complete and I had no complications being pregnant with the colostomy. It grew with my bump and functioned as normal.

Once again though, I had a Crohn's flare-up following Ayda's arrival. This time it didn't go into remission and after 12 months on prednisolone steroids, various antibiotics, multiple scans, scopes and tests I was referred back to the surgeon.

In the operation that followed, approximately 20cm of bowel was removed along with lots of complex fistulas tracking to different organs including the

colon, rectum and bladder. Due to the complexity of the operation, I had to wait almost 12 months before the decision was taken to go ahead. And, even then, the surgeon was unclear whether my rectum could be saved or whether a full proctocolectomy would be required. My employers were great and supported me even when I was spending the majority of the time tired and popping painkillers.

The surgical decision came as a shock. As a young Mum I had to prepare for major surgery again, so I started a blog on Facebook called *Stoma Mum* with the idea of helping others in same situation as me. The surgery date was eventually set for 14 March 2018 and I was put on a six-week 'ensure' diet to optimise my bowels and wean down the prednisolone from 40mg to 10mg. I managed to achieve this a few weeks before surgery. Coming round from surgery I didn't know what to expect, I was scared and nervous but after nine hours the operation was a success.

I class myself as fortunate. My surgeons did the best they could for me. They saved my rectum by stapling it off inside, leaving my rectal stump intact. My loop colostomy was made into an end colostomy and a hernia repaired. 30cm of small bowel and colon were removed along with fistula removal. A loop ileostomy was then formed as the re-join of the bowel at that point was considered risky and may not have attached due to the long term steroid use.

Now I have two bags and I have learnt quickly that two are very different. The ileostomy requires a drainable bag which has taken some adjusting to as I used a closed bag for years. I never feel fully clean and it takes time to get ready in a morning, but this is nothing compared to being incontinent as I was before the operation. They hope to reverse the ileostomy within



six months so eventually, all being well, I will just have the end colostomy which, at the minute, looks completely different to how it did when it was a loop colostomy.

I believe that the surgery saved my life and will give me a better quality of life with my two babies. It's early days as I only had surgery a few weeks ago but whether it's one or two bags I believe that with the right support and the right mind set I can achieve anything. I now look forward to the future. Crohn's disease is a disease that affects everyday life and I'm very lucky that my family support me always and love me unconditionally. No matter what the future brings I will keep fighting!

**Jodie Hookway**

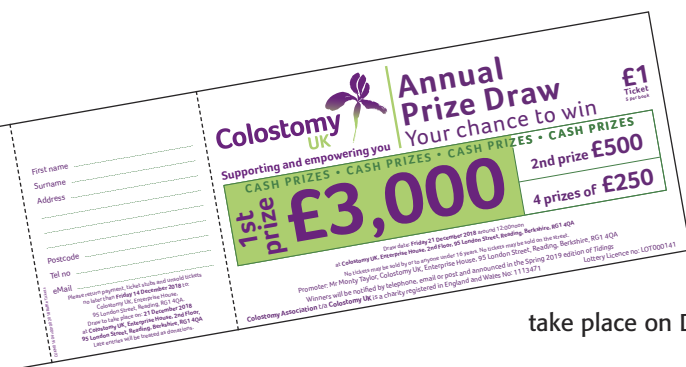


**To support Jodie visit:**  
[www.justgiving.com/fundraising/jodie-hookway](http://www.justgiving.com/fundraising/jodie-hookway)

# Fundraising focus



Giovanni Cinque – Fundraising and Development Manager



## 2018 Raffle

The response to our 2018 raffle has been fantastic so far! Tickets were enclosed with the last issue. If you have run out, then further books can be obtained by emailing us or calling **0118 939 1537**.

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

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



## Ian's Gateshead 10K run

On July 8 Ian Condon is competing in the Gateshead 10K to support **Colostomy UK**.

Ian has a permanent Ileostomy following surgery for bowel cancer. In his own words he is:

*"...taking on this challenge to help raise awareness, remove the stigma of having an ostomy and to continue offering help and support to ostomates across the UK."*

You can support Ian via his Just Giving page at:  
**[www.justgiving.com/fundraising/ian-condon](http://www.justgiving.com/fundraising/ian-condon)**

## Thank you!

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

- ❖ Ann Hughes raised £400 from her evening of Rock 'n' Roll at The Civic in Stourport.
- ❖ Betty Granger donated £250, the proceeds from her garage sale.
- ❖ Carr Mill Primary School in St Helens had a 'Purple day' and raised £250.
- ❖ Helen Oldknow 'Braved the shave' and donated £400.
- ❖ The Wessex Stoma Care Nurse Forum raised £80 from their annual raffle.
- ❖ Adele Louth took part in the Sheffield Half Marathon, finishing in a time of 2 hours 45 minutes, and raising £537.
- ❖ On May 12 Ryan Rees shaved his head in support of **Colostomy UK** and the Little Princess Trust and raised over £3,000.
- ❖ In April Emma Turner braved the Blenheim 7K run raising nearly £200.







## Unity Lottery

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

Members have the chance of winning a main prize of £25,000 each week (plus a £2,500 donation to **Colostomy UK**), as well as smaller prizes of five free draws, £25, and £1,000. Entry is only £1 per week and we receive 50p for every £1.



## Grants and Trusts

We are grateful to the following organisations that have recently supported **Colostomy UK**: The Childwick Trust, the Cardy Beaver Foundation, The Donald Forrester Trust, The Ganzoni Charitable Trust, Constance Travis Charitable Trust, The Deakin Trust, Payne-Gallway Charitable Trust, RG Hulls Charitable Trust, Coral Samuel Charitable Trust.

## Text giving

You can now make a donation to the **Colostomy UK** with a text message! Whatever mobile network you're on, simply text our unique code **CASS01** and an amount of £4, £5 or £10 to **70070**.

Donating via text is free. There is no cost to you for sending the text message and your free allowance or bundle will not be affected – the only charge will be the donation itself. What's more, 100% of your text donation (including Gift Aid) will be sent to **Colostomy UK**.

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

## Interested in fundraising for us?

A successful event doesn't need to raise huge amounts of money. Rest assured, whether it be £5 or £500, **Colostomy UK** will put it to good use. We are here to support your efforts in every way we can, including fundraising materials, sponsorship forms or just advice on where to start. To find out more contact Giovanni Cinque – [Giovanni.Cinque@ColostomyUK.org](mailto:Giovanni.Cinque@ColostomyUK.org) or call us on **0118 939 1537**.



## WHAT WILL YOUR LEGACY BE?

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

### What your gift means

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

- ❖ Ensure there is always a voice at the other end of the phone.
- ❖ Train volunteers to provide support at open days and in hospitals.
- ❖ Fund our campaign for a stoma friendly society.

### How to leave a legacy

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

Your solicitor will need the following information on our charity:

Name: **Colostomy UK**

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

Charity Commission registration number: **1113471**

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

Supporting and empowering you



## Looking for online support?

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

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

*We look forward to welcoming you.*

[www.ColostomyUK.org](http://www.ColostomyUK.org)

Freephone helpline:

**0800 328 4257**





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

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

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

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

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

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

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

Card number \_\_\_\_\_ (Maestro only)  
 Expiry date \_\_\_\_\_ Security code \_\_\_\_\_ (Maestro only) Start date \_\_\_\_\_ (Maestro only) Issue No. \_\_\_\_\_  
 D D M M Y Y

Signed \_\_\_\_\_ Date \_\_\_\_\_

*giftaid it* Thank you for your gift

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

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

Signature: \_\_\_\_\_ Date: \_\_\_\_ / \_\_\_\_ / 2018

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

To the Manager: (Bank or Building Society) \_\_\_\_\_  
 Bank Address: \_\_\_\_\_ Postcode: \_\_\_\_\_  
 Name(s) of Account holder(s): \_\_\_\_\_  
 Account number: \_\_\_\_\_ Sort code: \_\_\_\_\_

I would like to make a **regular donation\*** of ☐ £20 ☐ £30 or other amount (please state) £ \_\_\_\_\_  
☐ monthly ☐ quarterly ☐ annually starting on the ☐ 1st ☐ 15th ☐ 25th of month: \_\_\_\_\_ year: \_\_\_\_\_  
 thereafter until further notice. (Please cancel any previous standing order in favour of this beneficiary).

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

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

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

Name: (IN CAPITALS) \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_ / \_\_\_\_ / 2018

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

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

Registered Charity No: 1113471

 Registered with **FUNDRAISING REGULATOR**

# News from Local Support groups



## Coventry Stoma Support Group

Meet First Wednesday of every month.  
 Venue Christ the King Church library, 15 Westhill Road, Coundon, Coventry, CV6 2AA  
 Time 7:00pm till 9:00pm  
 Contact Martin 07947 385 643

**We regularly see 25 to 30 members every month, and have a guest speaker from one of the many stoma care companies, followed by refreshments, and then general informal discussion between ourselves on any subject that any member wishes to speak about. There are no membership fees, and all ostomates, relatives and their friends are welcome.**

We held our first, in house Christmas social meeting in December 2017, and it was a great success, so hopefully will become an annual event, and we will all continue to support each other through our group.



## Mid Devon Ostomy Support Group

I am a volunteer with **Colostomy UK** and was asked to start a support group in 2012. I have been running the Mid Devon Ostomy Support Group for just over five years now. We are a self-funded group offering support to local ostomates, their partners, friends and family. We usually have between 20–30 people come along.

We have three to four meetings a year at the Boniface Centre in Crediton on Saturday afternoons. These informal meetings are for people with any type of stoma. We do not have any membership fees and people are not obliged to come every time, however many do and make lots of friends in the process.

Our only outgoings are hire of the hall, the cost of light refreshments (tea, coffee, cakes) and sometimes a speaker to vary our meetings. People contribute towards these expenses and we also have a draw each meeting, which brings in some money that we hold as a float. We are also very fortunate that stoma reps come along and help with our costs. People like to see stoma reps and stoma nurses at our meetings. It gives them the opportunity to see and discuss the latest products and chat with the professionals about everything 'stoma'!

The feedback below should give you an idea about what happens at our meetings:

*"I think the success of your support group is the informality. It is a safe and relaxed atmosphere for people with a stoma to meet others who have lived the same or similar experiences and there is no pressure for anyone to discuss stoma related issues if they don't want to."*

*"I think the variety of speakers you have is brilliant and keeps the meetings short and interesting."*

*"It's good to chat about things such as travelling or exercises."*

*"Pat's homemade baking is always good with a cup of tea or coffee."*

My contact details:

**janice234ford@gmail.com** or **07923 975 051**





# Stoma Care Open Days

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

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

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

## Coloplast Event

The Moat House, Lower Penkridge Road, Acton Trussell, ST17 0RJ  
6 July 2018 10:00am–12:30pm  
Terry Anne Horncastle: 07770 494 727 or gbtah@coloplast.com or Julie Turner: 07469 144 186 or gbjtu@coloplast.com

## ConvaTec event

Tiffany Room Wymondham, Wymondham Central Hall Back Lane, Wymondham, NR18 0QB  
6 July 2018 01:30pm–03:30pm  
0800 83 48 22  
stoma.webcare@convatec.com

## ConvaTec event

Hallmark Hotel, Preston Leyland, PR25 4JX  
11 July 2018 2–4pm

## ConvaTec event

Rochdale Community Event, Mercure Manchester, Norton Grange, OL11 2XZ  
12 July 2018 2–4 PM

## ConvaTec event

Mecure Tunbridge Wells Hotel, 8 Tonbridge Road, Pembury, Tunbridge Wells, TN2 4QL  
14 July 2018 02:00pm – 04:00pm  
0800 83 48 22  
stoma.webcare@convatec.com

## Coloplast Event

House for an Art Lover, Bellahouston Park, 10 Dumbreck Road, Glasgow, G41 5BW  
14 July 2018 12:00pm–3:00pm  
Rebecca: 07810 057 682 or gbrpr@coloplast.com

## ConvaTec event

Cumbria Community Event, Washington Central Hotel, Cumbria, CA14 3AY  
25 July 2018 2pm–4pm

## West Suffolk Hospital Ostomy Open Day

Red Room at Tattersalls, Newmarket, Suffolk, CB8 2AY  
20 September 2018 10:30am – 3:00pm  
Katie Lloyd & Ann Hubble  
T: 01284 712 872

## National Support Organisations

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

### IA The Ileostomy and Internal Pouch Support Group

[www.iasupport.org](http://www.iasupport.org)  
Telephone 0800 0184 724  
e-mail [info@iasupport.org](mailto:info@iasupport.org)

### UA Urostomy Association

[www.urostomyassociation.org.uk](http://www.urostomyassociation.org.uk)  
Telephone 01386 430 140  
e-mail [secretary@urostomyassociation.org.uk](mailto:secretary@urostomyassociation.org.uk)

### Mitrofanoff Support

[www.mitrofanoffsupport.org.uk](http://www.mitrofanoffsupport.org.uk)  
Telephone 01202 674336  
e-mail [info@mitrofanoffsupport.org.uk](mailto:info@mitrofanoffsupport.org.uk)

### IOA International Ostomy Association

[www.ostomyinternational.org](http://www.ostomyinternational.org)

### Junior Ostomy Support Helpline (JOSH)

via the **Colostomy UK** 24-hour free helpline 0800 328 4257  
e-mail [info@ColostomyUK.org](mailto:info@ColostomyUK.org)

### Breakaway Foundation

[www.breakawayfoundation.org.uk](http://www.breakawayfoundation.org.uk)  
Telephone 01283 240253  
e-mail [info@breakawayfoundation.org.uk](mailto:info@breakawayfoundation.org.uk)

## Support Organisations for associated medical conditions

### Beating Bowel Cancer UK

[www.beatingbowelcancer.org](http://www.beatingbowelcancer.org)  
Telephone 020 8973 0000

### Bowel Cancer UK

[www.bowelcanceruk.org.uk](http://www.bowelcanceruk.org.uk)  
Telephone 020 7940 1760  
e-mail [admin@bowelcanceruk.org.uk](mailto:admin@bowelcanceruk.org.uk)

### Macmillan Cancer Support

[www.macmillan.org.uk](http://www.macmillan.org.uk)  
Telephone 0808 808 00 00  
Monday–Friday, 9am–8pm

### Crohn's and Colitis UK

[www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)  
Telephone 0300 222 5700  
e-mail [info@crohnsandcolitis.org.uk](mailto:info@crohnsandcolitis.org.uk)

### The IBS Network

[www.theibsnetwork.org](http://www.theibsnetwork.org)  
Telephone 0114 272 3253  
e-mail [info@theibsnetwork.org](mailto:info@theibsnetwork.org)

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

## Stoma support groups in your county

### Channel Islands

#### Channel Islands

Guernsey Ostomates  
Luci Deane 01481 236 077 /  
lucideane58@gmail.com  
Jersey Ostomy Society  
Fiona Le Ber: 01534 445 076 or  
jerseyostomysociety@gmail.com

### England

#### Bedfordshire

Saturday Social Club  
Karen Richards: 01234 792 278

#### Berkshire

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

#### Bristol

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

#### Buckinghamshire

High Wycombe Stoma Support Group  
Jan Peacock telephone 0800 318965,  
e-mail peaky461@gmail.com  
Milton Keynes Stoma Association  
Thia Cooper 01908 679 295 /  
mksa.chair@gmail.com  
You Are Not Alone Stoma Support  
Group  
Carla 07846 354 918 e-mail:  
carla\_wright@sky.com

#### Cambridgeshire

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

#### Cheshire

Countess of Chester Hospital Stoma  
Support Group  
Stoma Nurses 01244 366 170  
East Cheshire Stoma Support Group  
Catherine McIntosh: 01477 535 071  
Stockport Support Group  
Marion Caulfield: 0161 320 9400 /  
0800 652 6667  
Warrington Ostomy Support Group  
Jane Shaw: 01925 662 103

#### Cleveland

Oops Group  
Julie Morrisroe/Carol Younger/Alison  
Hall-O'Donnel: 01287 284 113

#### Cornwall

Cornwall & Plymouth Bowel Cancer  
Support Group  
The Chairperson: 01726 828 419 or The  
Secretary: 01872 241 145,  
cbcsinfo@gmail.com or website  
[www.cornwall-bowel-cancer-support-  
group.co.uk](http://www.cornwall-bowel-cancer-support-group.co.uk)  
Cornwall Ostomy Support  
Ken Jones: 01872 863 106 or  
[www.cornwallostomysupport.org.uk](http://www.cornwallostomysupport.org.uk)  
Lanhydrock Ostomist Group  
Mandy Rowe: 01726 832 642  
E: [murphy.rowe781@btopenworld.com](mailto:murphy.rowe781@btopenworld.com);  
Henry Kendall: 01208 850 986  
E: [h.kendall380@btinternet.com](mailto:h.kendall380@btinternet.com)

#### County Durham

Bishop Auckland Stoma Care Group  
01388 814 535 or email-  
[pgill82171@aol.com](mailto:pgill82171@aol.com)  
Darlington Support Group  
Sister Jacqui Atkinson: 01325 743005  
Durham Stoma Support Group  
Sister Maxine Santana -0191 333 2184

#### Cumbria

Grange Cancer Support Drop in  
Marie O'Connor 015395 33279  
Stoma Support Groups in North  
Cumbria  
Stoma Care Nurses 01228 814 179

#### Derbyshire

Diverted Local Stoma Support Group  
Diana Manning: 01283 541 311

#### Devon

Devon IA  
Martin Hornby: 01458 251 095 or  
email: [devon@iasupport.org](mailto:devon@iasupport.org)  
Mid Devon Ostomy Support Group  
Janice - [janice234ford@gmail.com](mailto:janice234ford@gmail.com)  
Plymouth & District Bowel Cancer  
Support Group  
Wendy Wilson or Keith Anderson:  
07934 922 156 Facebook: Plymouth  
Bowel Cancer

#### Dorset

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

#### Essex

Connect  
Lin Hart 01279 505 273 email:  
[comeconnectwithus@gmail.com](mailto:comeconnectwithus@gmail.com)  
Mid Essex Stoma Support Group  
Paul Foulger: 01245 224 374  
N.E.S.S (North Essex Stoma Support)  
Brian Waller- 01206 540 449  
Optimistic Ostomates  
Angela Taylor 01702 385510  
Redbridge Ostomists Club  
Stoma Nurses - Chris/Lisa: 020 8970  
8321  
STEPS - Stoma Essex Patients Support  
01268 451 937 or email-  
[stepsessex@gmail.com](mailto:stepsessex@gmail.com)

#### Gloucestershire

Vale Stoma Support Group  
[jfn.dursley@gmail.com](mailto:jfn.dursley@gmail.com) or text 07941  
827 393





## Hampshire

Replummed stoma support group  
www.replummed.me

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

Sally - 07527 707 069

Southern Ostomy Group

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

Waterside Stoma Support Group

Hazel Derham: 02380 891 934 or  
hayjuder@sky.com

Wessex Urology Support Group

Adrian Kuczynski: 07910 786 978

## Herefordshire

Herefordshire Stoma Support Group

Carol Steele 01432 880 656 or email:  
carolsteeleglo@gmail.com

## Hertfordshire

Colonise

Anastasia 01727 760 981

Stevenage Ostomistics

Judy Colston: 01438 354 018 /  
neilcolston@btinternet.com

## Isle of Man

IOM Bowel Cancer Patient and Carer Group

Heather Norman: 07624 480 973

Stoma Support Group

Carole Cringle stoma nurse: 01624 650 212

## Isle of Wight

Optimistics

CNS's Sarah Capon & Sarah Varma  
01983 534 009

Semi-Colon Club

Tony Crowson on 01983 559 326 or  
Cancer Clinical Nurse 01983 534 180

## Kent

Ashford Stoma Support Group

Carole Hobbs: 01303 814 014 or  
Margaret Webb 01233 628 807

Atoms Support Group

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

Dartford Ostomy Group Support (DOGS)

"Tracey, John or Sue: 07948 974 350 or  
dogs-uk@hotmail.com"

Dover Stoma Friends Group Support

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

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

Helen Or Tracey: 07773 605 534

Maidstone Stoma Support Group

Judy/Kirsty: 01622 224 305

Sheppey Ostomy Group Support (SOGS)

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

SWANS Stoma Support Group

Heather - 07711 445 312

Thanet Stoma Buddies Support Group

Kathy 01843 291825

Tunbridge Wells Stoma Support Group

Cathy Chitty/Mags Donovan 01892 632 323

## Lancashire

Kangaroo Klub, Blackpool stoma support group

For further details please contact the stoma department at Blackpool Teaching hospitals, Tel: 01253 956620 or e-mail crc-stomanurses@bfwhospitals.nhs.uk

North Manchester and Bury Stoma Support Group

Julie Meadows (SCN) 0161 720 2815 or  
07774 263 563

Oldham Stoma Support

June Wilde: 0161 312 5538

Phoenix Bowel Cancer Support Group

Sandra Peet: 01772 683 790,  
www.phoenixgroupbvh.com or eMail:  
sandrapeat7@aol.com

## Leicestershire

Kirby Ostomy Support Group.

Colostomy, Ileostomy and Urostomy in Leicestershire

Janet Cooper: 0116 239 2844 /  
kosg2013@btinternet.com

## Lincolnshire

Friends East Coast Support Group

Betty Williams - 01205 724 120, Sheila - 01205 364 493

Grantham Support Group

Bobbie/Rachel: 01476 464 822

## London

Bowel & other Cancer Support Newham

020 8553 5366 scyana@tiscali.co.uk

Homerton Hospital Bowel & Stoma Support Group

Angela Davy: 0208 510 5318 or 0208 510 7599

Rectangle - Colorectal Cancer Support Group

Regina Raymond 0207 472 6299

South Woodford Support Group

Nurse Christina and Lisa: 0208 535 6563

Surrey & South London Bowel Cancer Support Group

Sue Berry: 01737 553 134 or John Amos: 0208 668 0796

## Merseyside

I.C.U.P.S

Sue: 07742 237 013

St Helens Cancer Support Group

01744 21831, Denys Floyd- 01744 884097 or email:  
contact@sthelenscancersupportgroup.org

## Middlesex

Inside Out

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

## Norfolk

James Pagett Ostomy Support Group (Afternoon Meeting)

Vicki Blackwell on 01493 663 363

James Pagett Ostomy Support Group (Evening Meeting)

Sandra Hutchings: 0150 258 5955

Kings Lynn Ostomy Friendship Support Group

For more info please call 01553 775 698 / 01553 674 962 / 01553 768 271

## Norfolk Ostomates

Barbara Harris 01603 417046 07789 581312 ""Norfolk Ostomates""

Facebook group"

STARS (SToma And Reconstructive Surgery social support group )

Sylvia Hughes 01263 733448  
sylvia.ruth.hughes@gmail.com

## Northamptonshire

Northampton Ostomy Support Group

07801 316 403 (evenings) or Trish 07703 188 386

## Northumberland

Berwick Ostomy Support Group

Bobbie Minshall: 07714 479 320

Hexham Ostomy Group

Judith on 07967 927 286

Northumberland Cancer Support

members@northumberlandcancersupportgroup.co.uk

## Nottinghamshire

North Notts Stoma Support Group

Tore and Nicky Norman: 0177 371 5460

Nottingham QMC Stoma Support Group

Rosemary Brierley: 0115 982 6691

Nottingham Stoma Support

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

## Shropshire

B.O.T.S. (Bums on Tums)

Irene Constable on 0169 123 8357

## Staffordshire

Outlook

Moirra Hammond 07788 402 195

## Suffolk

East Suffolk Ostomy Group

Marion Fisher: 01473 311 204

L.O.G.S (Lowestoft Ostomy Group Social)

Mandy O'Shea: 07899 913 617 or  
Bruce Pollard: brucepollard@me.com

West Suffolk & District Stoma Group

Jessica Pitt stoma nurse: 0163 851 5525

## Surrey

Epsom and District Stoma Support Group

Lindsay, Trevor or Sheena: 01372 735 925

Normandy Colostomy Support Group

Marina Harkins: 01483 233 126 or  
07852 554 049 or Jackie Sanders:  
jackie-sanders@hotmail.co.uk or 07815 603 742. Website:  
www.normandystomagroup.wordpress.com

Stoma Support Group

Robin Young: 01428 723 255

## Sussex

Brighton & District Support after Stomas (SAS)

Sylvia Bottomley: 01273 554 407

Chichester Stoma support Group

The Stoma Care Team 01243 831 527

The Ostomy Friends Group

Jane Quigley: 01323 417 400 ext 4552

West Sussex Princess Royal Stoma Support

Tina Walker: 01444 441 881 ext 8318

## SUPPORT

### Tyne and Wear

Gateshead Stoma Patient and Carer Support Group  
Stoma Care Nurses: 0191 445 3152 or email [stuart.sutcliffe81@yahoo.com](mailto:stuart.sutcliffe81@yahoo.com)  
NHS Molineaux Centre  
John Burchell 0191 265 1047  
Royal Victoria Infirmary Support Group  
John Burchell 0191 265 1047

### Warwickshire

Warwickshire Stoma Support Group  
[nuneatonstoma@aol.com](mailto:nuneatonstoma@aol.com) or Bob: 07564 680 803

### West Midlands

Coventry Stoma Support  
Martin - 07947 385 643

### Wiltshire

Swindon IA  
[www.swindon-ia.org.uk](http://www.swindon-ia.org.uk)  
Wessex Stoma Support Group  
Michael Slater:  
[wessex.stoma@yahoo.co.uk](mailto:wessex.stoma@yahoo.co.uk) or on 01722 741 233 [www.wessex-stoma.co.uk](http://www.wessex-stoma.co.uk)

### Worcestershire

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

### Yorkshire

Acorn Ostomy Support Group  
07580 693 155 (After 6-00pm)  
Airedale Stoma Support  
Sue Hall: 01535 646 373  
Barnsley Bottoms Up Stoma Support Group  
Stoma Nurses 01226 4325 28 or Celia Utley (Chairman) 01226 284 262  
Behind You (Calderdale & Huddersfield Bowel Cancer Support Group)  
Stoma Care Nurses: 01484 355 062  
Bottoms Up (for urology and colorectal cancer patients)  
John Whelpton 0797 4657146  
Dewsbury & District Ostomy  
Janet Edmond: 01924 512 041 or 01924 512 072  
Hambleton and Richmondshire Ostomy Support Group  
Stoma Care Nurses - Judith Smith and Mary Hugil 01609 764 620 / 07736 295 131  
Harrogate Stoma Support group  
Jacquie- 07768 024 356  
Leeds Bowel Cancer Support Group  
Lynda Castle (Colorectal Nurse Specialist) 0113 206 5535  
Scarborough Stoma Support Group  
Stoma Care Team: 01723 342 388  
The Hull and East Riding Colostomy Support Group  
Pete Smith: 07989 565 335 or Pete Rennard: 07939 518 642 / 01482 793 966 or Rosanna Grimsby: 01482 801 575. [www.hercosg.org.uk](http://www.hercosg.org.uk)

## Northern Ireland

### County Antrim

Colostomy UK Volunteers Northern Ireland  
Chris Wright: 07720 717 771  
Mater Hospital  
Karen Boyd - Stoma Nurse: 028 9074 1211 Ext 2329  
Royal Victoria Hospital - Belfast  
Sarah Haughey/Audrey Steele: 028 9024 0503 Ext 3483

### County Armagh

Craigavon Area Hospital  
Clare Young/Lynn Berry/Janice Garvie 028 3861 2721  
Daisy Hill Hospital Support Group  
Bernie Trainor: 028 3083 5000 Ext 2222

### County Down

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

### Londonderry

Causeway Support Group  
Mary Kane: 028 7034 6264

## Scotland

### Ayrshire

Ayrshire & Arran Stoma Support Group  
Jim Krasewitz: 01292 220 945  
Stoma Care And Recovery (SCAR)  
Maggie: 01294 271 060/ 0781 773 6147 [maggie13@sky.com](mailto:maggie13@sky.com) or Rhona: 01294 557 478

### Fife

Fife Ostomy Support Group  
Ishbel Barr: 01592 772 200

### Lanarkshire

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

### Moray

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

### Scottish Borders

Stoma Support Group  
Nancy Fraser: [nancyfraser@talktalk.net](mailto:nancyfraser@talktalk.net) or 01450 374 012. Fiona Gentleman: [r.gentleman@sky.com](mailto:r.gentleman@sky.com) or 01450 371 063

### West Lothian

Bring Your Own Bag Stoma Support Group  
Western General Stoma Team 0131 537 1000  
GOSH (West Lothian)  
Scott Pattison: 07502 163 644

## Wales

### Bridgend

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

### Carmarthenshire

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

### Conwy

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

### Flintshire

Bag For Life Stoma Support Group  
In.It.Together  
Faye Jones 07852 750 772

### Gwent

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

### Mid Glamorgan

C.A.S.S Colorectal and Stoma Support Group  
Colorectal Nurse Team on 01685 728 205

### Pembrokeshire

PSA (Pembrokeshire Stoma Association)  
Roy Whitfield 01437 760 701

### Powys

The Bracken Trust Cancer Support Centre  
Helen Davies: 01597 823646

### Rhondda Cynon Taf

Royal Glamorgan Stoma Care Support Group  
Domenica Lear 01443 443 053

### Swansea

Swansea Ostomy Self Help Group  
Glynis Jenkins: 01792 418 245

## Republic of Ireland

### County Mayo

Mayo Stoma Support  
Marion Martyn: +353 (0)949 021 733

### Dublin

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



**Do something amazing!**

Join Team Colostomy UK.  
Together we can make a difference.

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



[fundraising@ColostomyUK.org](mailto:fundraising@ColostomyUK.org)  
**0118 939 1537**

[ColostomyUK.org](http://ColostomyUK.org)

Supporting and empowering you



## We are Colostomy UK.

### Here to support you:

- **24-hour free helpline:** 0800 328 4257.
- **Information booklets, leaflets and factsheets.**
- ***Tidings*** our flagship support magazine.
- **A closed Facebook support group** for ostomates to support each other and exchange hints and tips.
- **A website** packed full of useful information

### Here to empower you:

- **Campaigning** to raise awareness and bring about positive, tangible changes for people living with stomas.
- Running **Projects** to help ostomates reach their potential.
- Acting as **advocates**. We are your voice on the bigger issues.

Contact us

**Freephone helpline:**

**0800 328 4257**

**E:** [info@ColostomyUK.org](mailto:info@ColostomyUK.org) | **W:** [www.ColostomyUK.org](http://www.ColostomyUK.org)

