Winter 2022 | Issue 68 | £6.25

Colostomy UK

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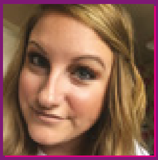
Tidings

Supporting & empowering ostomates

Merry Christmas and a Happy New Year to All Our Readers!



PAGE 21

Endometriosis and an Emergency Stoma: Kathryn's Story

PAGE 30

A Bear Named Buttony: Jenny Gow

Real stories Real people

Good Tidings we want to bring

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Did you know that each issue costs us £6.25 to produce, that's £25 a year for each reader.

This Christmas can you donate £25 to Colostomy UK so that someone else in need gets the same support you did?

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Dear readers

Happy Christmas from everyone at Colostomy UK! I know there are still a good few weeks to go, but hopefully your preparations are well underway.

If so, then relax with the winter edition and give yourself a well-earned breather. Or, if you are one of those last-minute people, then make this copy of Tidings your excuse for delaying starting just one more day… Personally I identify more readily with the 'leave it 'til Christmas Eve crowd'. But this year, with all the family coming over, I have had to be more organised. I can even admit to feeling a bit Christmassy, probably because the family now includes my little grandson Henry, who is now nearly walking. My daughter, who as a paramedic, usually ends up working over Christmas will also be home.

In this edition instead of Dear Nurse, we have Dear Dietitian. Pooja Dhir who is a specialist dietitian and has previously written for us on stomas and hydration (winter 2021), gives some valuable advice about eating over the Christmas period. As you will see, what she has to say goes further than simply warning about over-indulgence! Sticking with the professionals, Dr Benjamin Saunders, who is a lecturer at Keele University in Applied Health Research, gives a summary of the latest stoma research. Importantly, he also explains what this might mean for stoma care and people with stomas.

Coming from a research background myself, I'm well aware how the work at universities can sometimes seem distant and even irrelevant to people. Hopefully this piece will go some way to addressing this issue!

We have three Real Lives stories, kicking off with one from our volunteer Bernard Tinker, who talks a little about the history of pantomime and his involvement with pantos (before and after stoma surgery). It's not your usual real lives story, but it's certainly appropriate for the time of year (Oh no it isn't!). Our second uses Kathryn Watson's story as a lens through which to examine endometriosis and emergency stoma surgery. This is an aspect of women's health that doesn't get the attention it deserves. Lastly, we hear about Jessica who has had a stoma since she was four years old. Jessica's story is also entwined with our final article which is all about A Bear Named Buttony. Set up in 2015, this charity plays a vital role helping children who are about to have stoma surgery, as well as supporting their parents.

And, finally, there is all the usual news from Colostomy UK, including an enlightening piece put together with the help of our volunteers, all about the sorts of calls we get to the Stoma Helpline.

See you in the New Year!

Best wishes,

Richard Biddle
Editor, Writer & Researcher

Colostomy UK

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

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

How to contact us

Stoma helpline for:

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

Adminline for:

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

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Contents

Colostomy UK News

6 Colostomy UK: **News**
18 **Volunteers**
34 **Active Ostomates**
36 **Campaigns**

Real Lives

9 **A Tale of Pantomime - "OH, YES IT IS!"** – By Bernard Tinker
21 **Endometriosis and an Emergency Stoma: Kathryn's Story** – By Richard Biddle
26 **Jessica's Stoma Journey: Kim Lucock** – By Jillian Matthew

Wellbeing

14 **Research Round up** – By Dr Benjamin Saunders
24 **Dear Dietician** – By Pooja Dhir
30 **A Bear Named Buttony: Jenny Gow** – By Jillian Matthew

Fundraising

38 Colostomy UK: **Fundraising**

Support

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

Donating to Colostomy UK

An annual donation of £25 (or what you can afford) allows us to produce Tidings and to continue our vital work, supporting, and empowering ostomates – see page 45 for our donation form.

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

Colostomy UK

news

Libby Herbert
CEO
Libby.Herbert@ColostomyUK.org

Colostomy UK Volunteers Win Prestigious League of Mercy Awards

We are proud to report that long-standing volunteers Sue Hatton and Irene Constable have received Order of Mercy awards for their outstanding work helping and supporting people with stomas.

The League of Mercy was established by Royal Charter in 1899 and became a registered charity in 1999. Their central aims are to encourage and recognise distinguished voluntary work in areas of care. They make just twenty-five awards each year.

As you can imagine the conferral ceremony befitted the prestigious nature of the awards. By kind permission of the Rt Hon the Lord Mayor of London, it was held at the Mansion House, City of London and led by the Rt Hon The Lord Lingfield, who is the president of the League. After the formal address Sue and Irene, accompanied by their husbands and Libby Herbert (Colostomy UK's CEO) and Jo McKenzie (Colostomy UK's Senior Support Co-Ordinator) enjoyed a buffet lunch and were able to meet other proud recipients along with trustees and friends of The League, the latter of which included HRH Princess Katarina of Yugoslavia!

Judy Pullen Retires

Everyone at Colostomy UK wishes Judy Pullen a happy retirement and thanks her for the support she has given us over the years.

Judy worked as a nurse for five decades, first at the Princess Margaret Hospital and then the Great Western Hospital in Swindon where, as Clinical Nurse Specialist, she was in charge of a busy stoma care department. If you would like to read more about Judy's career and about life in a stoma care department, then look no further than the winter 2019 edition of Tidings. If you don't have this in hardcopy, it is free to download via the support tab on our website.

Colostomy UK Annual General Meeting (AGM)

Our AGM took place on Saturday 9 July.

Just like last year, this was held 'virtually', to make it easier for people to attend from across the country. As well as covering all the usual requirements of an AGM, we used the opportunity to present to attendees in more detail some of the work we have been doing and our plans for the future.

The Team is Out and About Again!

It was a busy autumn with members of the Colostomy UK team attending a number of important events.

OCTOBER

Just as we went to print, Mandi Laing (Chair of Trustees) and Libby Herbert (CEO) headed up to the Harrogate Convention Centre for the Association of Stoma Care Nurses (ASCN) annual conference. This is an important event for us, particularly as two sessions on the second day are set aside for charities. It's a good platform for us to showcase what we do and how we can work with stoma care nurses for the benefit of patients.

Also in October, Giovanni Cinque (Fundraising & Campaigns Manager), Jacqui Ramsey (Fundraising & Communications Executive) and our volunteer Pete Vernon will be attending the Best Practice Show at the NEC in Birmingham. This is the UK's number one event for the Primary Care and General Practice Community with over 7,000 GPs, pharmacists, and Practice Managers attending. We are hoping to provide the delegates with lots of information about how we can help them and their patients who have stomas. A big thank you to SecuriCare for sponsoring our attendance and to Sally their stoma care nurse for supporting and helping out on our stand.

NOVEMBER

Then in November Giovanni, along with our volunteer Lucy Hart will be returning to the NEC, this time for the Occupational Therapy Show. This event brings together thousands of allied health workers. For us, it's a great opportunity to raise the profile of Colostomy UK outside of traditional stoma care settings and engage with healthcare professionals who, in the course of their work, are involved in the treatment and care of ostomates.

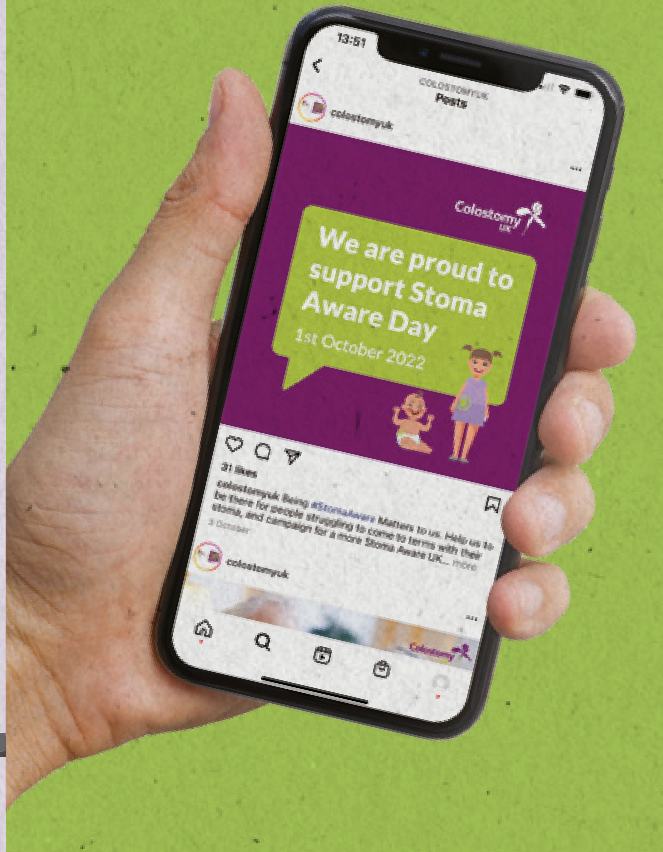
StomaAware Day 2022

Our Fourth Stoma Aware Day took place on 1 October. Our campaign theme was 'being Stoma Aware matters'.

To us being Stoma Aware matters because it helps to tackle prejudice and discrimination, which in turn reduces isolation and loneliness; empowering people to live life to the full.

To acknowledge the day, we asked people to tell us and their wider community of friends and followers why society being Stoma Aware matters to them. We had a really positive response with some great coverage generated online and in the media. It was also awesome to see the Mersey Gateway Bridge lit up in Purple to celebrate the day. A big thank you to our front cover star Jessica, and her mum Kim for arranging this.

To get involved with our campaign visit **www.ColostomyUK.org/campaigns**



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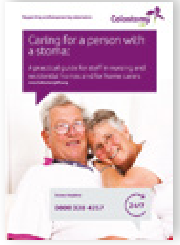
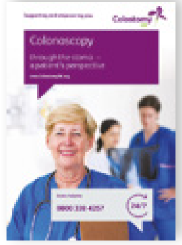
Active Ostomates sport and fitness after stoma surgery


Campaigns and Projects Flyer


Caring for a person with a stoma


Caring for a person with a stoma and dementia

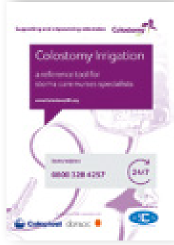

Colonoscopy through a stoma


Fundraising Pack


Healthy Eating

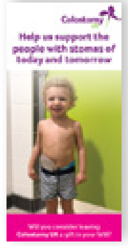

Helpline Cards

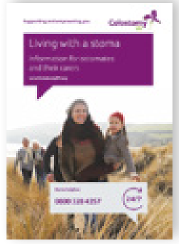

How will a stoma affect me?

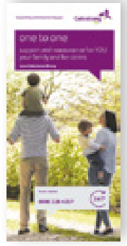

Irrigation Booklet


Irrigation DVD (nurses)


Irrigation DVD (patients)


Legacy Flyer


Living with a stoma


One to one


Ovarian Cancer and stomas


Pain and discomfort

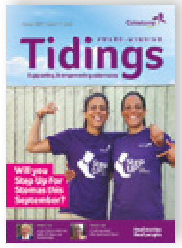

Parastomal hernias


Rectal discharge


'Sam has a stoma' colouring book

Stoma friendly toilet guideline and stickers


Stoma reversal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Welcome pack

A Tale of Pantomime – "OH, YES IT IS!"

BY BERNARD TINKER

I think we all recognise that the annual pantomime is most children's introduction to live theatre. The magic of this experience is hopefully one that lasts with them forever. For many theatres, both urban and provincial, and even local village halls, this annual event is their lifeblood. The income it generates is often enough to see them through the leaner times. When I had my colostomy formed in 1996, following a bowel blockage caused by diverticulitis, I had already been involved in local pantos for twenty years.

Soon after my surgery I picked up where I left off; it was a momentary interruption to a theatre career that now spans six decades, during which I have produced and directed over 40 pantomimes and written or co-written about 25. So, 'without further ado' I'd like to share some of the stories and myths behind the tales which we all (well, most of us) enjoy.

Pantomime's origins can be traced to the early seventeenth century and the Italian 'Comedia del Arte', when travelling productions would be staged, sometimes in drama and/or dance, involving characters such as Harlequin and Columbine, Scaramouche, Pantaloon and Clown. These productions evolved over time and came to England where they were well received. By the early nineteenth century 'Harlequin' shows had become more of a burlesque, dominated by the great clown, Joseph Grimaldi who invented probably the most traditional gag of all. We've all shouted, "He's behind you" etc., and to this day, that's still called a 'Joey-Joey'.

Of course, we all know the basic plot is boy meets girl, but any fool can see the boy is played by a girl and the funny old woman is a man. In the long-skirted Victorian era, it was an excuse for the audience to see women's legs for the Principal Boy (Girl) wore tights. Leading ladies of the 'legitimate' theatre often refused to wear the outrageous costumes demanded of them and so comedians stepped into the breach and the 'Dame' was born.

In Victorian times and right up until World War Two, many pantos were written in rhyming couplets. But this can become boring after a couple of hours-worth, so nowadays it is usually only the immortals who speak in rhyme e.g. The Good Fairy and the Demon King/Wicked Witch. The Pantomime Aladdin was first played in London in 1788 and turned into a burlesque in 1861. This was followed a year or two later by Cinderella. This pantomime took a form that would just about be recognisable to us today; modern pantomime was born.

"What about the plots?" I hear you cry. Like most things, many of these stories go back a very long way.

The story of Cinderella, still the most popular pantomime, is known throughout Europe and Asia in about 400 versions and can be traced back to a book printed in China around AD 850. It is believed to derive from a pagan myth of Day (Cinderella) meeting difficulties at midnight and needing the Sun (Prince Charming) to save her. The Sleeping Beauty theme appears in Scandinavian legend and Sinbad was originally a Persian story translated into Arabic in the ninth century AD. It is widely believed that Jack the Giant Killer of Jack and the Beanstalk fame, is based on one Tom Hickathrift, an Anglo Saxon who defeated a Viking Giant at Ely (a David and Goliath scenario) although other parts of England have their own variations of who the Giant Killer actually was. Aladdin also has an interesting epithet. Apparently, in ancient China, many husbands went away to sea to seek their fortunes. Unfortunately, in those perilous times many did not return. Their wives, left alone, became known as 'Widow Twan Keis' and behold a Dame was born, Aladdin's mother, Widow Twankey.

Of course, the theatre is well-known for being full of tradition and superstition. The expression 'break a leg' is used because someone who was wished good luck as they were about to go on, promptly tripped and broke their leg. The Good Fairy should always make her entry from the 'Prompt side' Stage Right (the audience's left) because she is on the side of 'Right'. Stage Left (audience's right) is for the villain unless he happens to be rising through a trap door but even that is usually left of centre. 'Sinbad the Sailor' is considered to be an unlucky show because in the late 1890s at a dress rehearsal in Drury Lane a huge model eagle which was supposed to fly in and carry off Sinbad fell from the flies killing a cast member.

Another legend concerns Dick Whittington who, as we know, actually existed and was thrice Lord Mayor of London. His story is the time-honoured rags to riches plot but apparently Dick Whittington's 'cat' was actually a coal barge – so-called 'cats' and the Merchant's barges were used to bring coal to London during a freezing winter, thereby helping to 'save' London. Clearly the definitions have become marred over the centuries, but I do think the idea of its being a moggie is the more romantic one.

In recent years the Principal Boy (Girl) has tended to be replaced by a male (more pc, I suppose), although back in the 1960s I saw Cliff Richard playing Aladdin at the London Palladium. The Dame, however, still appears to be a part for a man. It used to be the case that at some point, Widow Twankey would have to put Aladdin across her knees and sew up his trousers which had split in the derriere. Psychologists say that when a Dame gets whitewashed, gunked or a custard pie in the face (slapstick is known as a 'slosh' scene) children only laugh because they know it's a man. If it were a woman – a mother or grandmother figure - they would be horrified.

Perhaps, not surprisingly nowadays, youngsters appear to identify more with the villain. He is believed to derive from the Evil One in medieval morality plays. One actor well known for playing parts as a panto villain has commented, "I have as many friends among the boys as enemies amongst the girls. I make them hiss and boo and tower over them like a big black spider. They enjoy the feeling of mild fear and apprehension, especially as I let them off the hook by ending with a ridiculous threat, shouting:

"All the doors are locked. There's no escape. I'm coming down there to steal your ice creams."

Naturally, all audiences want to laugh and join in, so any decent pantomime will be littered with jokes and gags. Is there a difference? Well, yes: a joke will often be a one or two-liner possibly with an insult aimed at one or the other character. For example:

> *1st Ugly Sister: (SOBBING)*
> *Boo-hoo, my foot won't fit*
> *into the crystal slipper.*
>
> *2nd Ugly Sister: Your foot wouldn't*
> *fit into the Crystal Palace!*

(younger audiences might not understand this at all!) Or:

> *Dame: My cooking*
> *should be Cordon Bleu*
>
> *Comic: Your cooking*
> *should be cordoned off*

Or again:

> *Dame: I've had a very trying day.*
>
> *Man: Have you really?*
>
> *Dame: Yes. The butcher tried,*
> *the milkman tried and the*
> *baker tried……*

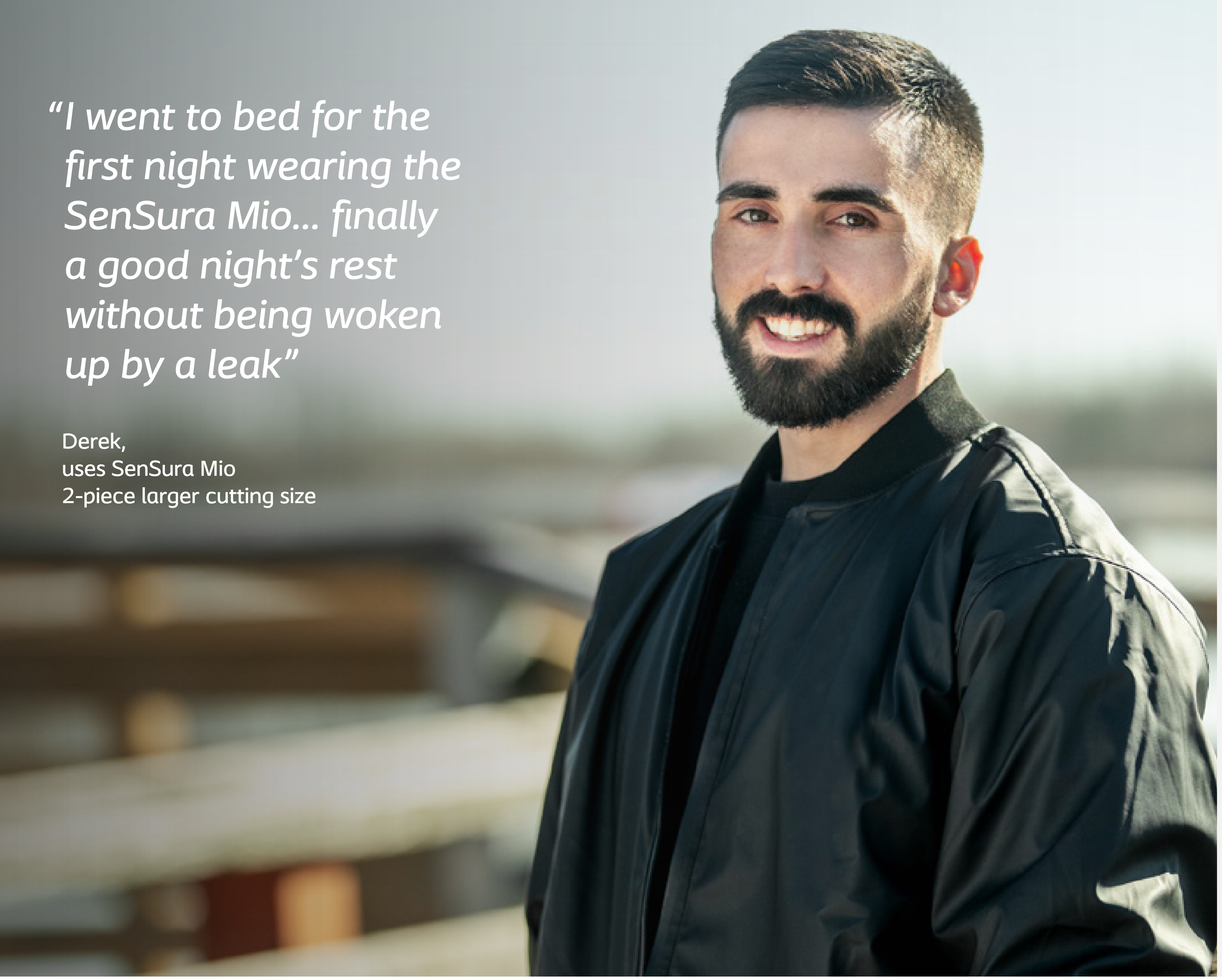
A pantomime 'Gag' is different. While it can also be a joke in common parlance, in panto it is an ongoing piece of comedy which may run for part or even the whole show. Just one example: in some productions of Cinderella there is a large red button contraption on one side of the stage. This may well be labelled or the audience told that it is known as "Button's Button". There is also a "Do not touch" notice. Buttons will ask the audience to shout for him if anyone goes near it or tries to press it.

Inevitably, during the course of the show several people hover over it and the audience screams for Buttons who rushes on just in time. Eventually, Buttons will confess that he doesn't know what it's for and asks if 'we' should press it. Naturally the answer is "Yes". Having done so it will summon another character such as the Good Fairy or Fairy Godmother. There are literally dozens of 'Gags' (such as the "Ghost scene" with a bench) which can nearly all be adapted for inclusion in any show. I could go on, but you've probably had enough by now… "Oh, yes you have!"

I'll finish by saying that contrary to some people's ideas we DID NOT have our senses of humour surgically removed at the same time as our operations. So, if you feel like giving it a go and treading the boards or getting involved in your local pantomime (it really is terrific fun) I'm very willing to offer any help, advice on organisation, planning or scripts at no charge, although a donation to CUK would, of course, be very welcome.

Please go and see a pantomime this Christmas. It's a uniquely British tradition; you won't find anything like it anywhere else in the world – "Oh, no you won't!"

Editor's note: Bernard is one of our volunteers and a member of our Stoma Helpline team. He attends open days and supplier events on our behalf too. Bernard lives in Dorset where he is an active member of the local West Dorset stoma support group C.U.P.I.D. (Colostomy, Urostomy, Pouch & Ileostomy Dorset)



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Coloplast

Research Round up

Dr Benjamin Saunders
Lecturer in Applied Health
Research, Keele University.

Research aiming to improve our understanding of the care and support needs of people with a stoma is something I'm extremely passionate about and have been involved with for years. In future editions, I look forward to giving you a summary of recently published research, which I hope you'll find informative.

For this edition, I've picked four studies exploring different aspects of stoma care and experience.

STUDY 1

The first focuses on online information about stomas.

Many of us turn to the internet for information about our health but knowing which sources to trust can be difficult. Researchers in Saudi Arabia investigated this problem through analysing the accuracy of YouTube videos about colostomy and ileostomy. During one week in May 2019, they identified 149 YouTube videos that discussed colostomies or ileostomies, using criteria to rate the educational value of each video. These criteria were developed based on the opinions of 20 medical experts, and clinical guidelines from the USA, UK and Canada.

The researchers found 52 videos (35%) met their criteria for being "educationally useful". The other 97 (65%) were judged to be "not educationally useful". Educationally useful videos were grouped into four categories: 1. videos covering surgical procedures; 2. self-care and bag changes; 3. those focusing on knowledge about colostomy or ileostomy; 4. impact on life/living with a stoma. Perhaps unsurprisingly, most educationally useful videos were created by stoma charities and organisations, or by health professionals.

The reasons for videos being categorised as not educationally useful included that the information wasn't scientifically accurate, the demonstrator didn't follow standard hygiene practices, or the advice given wasn't based on current evidence. The number of times videos had been viewed, their length, number of likes and the number of comments they received, were not significantly different between educationally useful videos and non-useful videos.

Whilst these findings paint a somewhat bleak picture about the quality of stoma videos on YouTube, there are some things we need to take into account. Firstly, whilst this article was published recently, the videos included were identified during a one-week period in 2019. This only gives a snapshot of the videos that were available at the time, and the quality of the videos on YouTube may have changed in the three years since. Additionally, the lack of scientific accuracy in videos may not necessarily mean they aren't useful. Ostomates may still find value in some of these videos, for instance in giving reassurance and support. My take-home advice is to always check the accuracy of any online medical information with reliable sources, such as your healthcare team, or organisations like Colostomy UK.

STUDY 2

The second study selected explored people's experiences of performing abdominal exercises after stoma surgery.

Fourteen Danish ostomates, aged between 20 and 73, with a newly formed ileostomy or colostomy, were interviewed after trying out a range of abdominal exercises.

The participants did up to 11 different abdominal exercises during a single 60–90-minute session. Participants whose surgery was very recent (0-2 weeks), performed gentle exercises lying or sitting on a hospital bed. Those who were 2–6 weeks' post-surgery performed exercises a little more demanding, sometimes sitting on an exercise ball. Participants who were 6-12 weeks' post-surgery did exercises that were more challenging still.

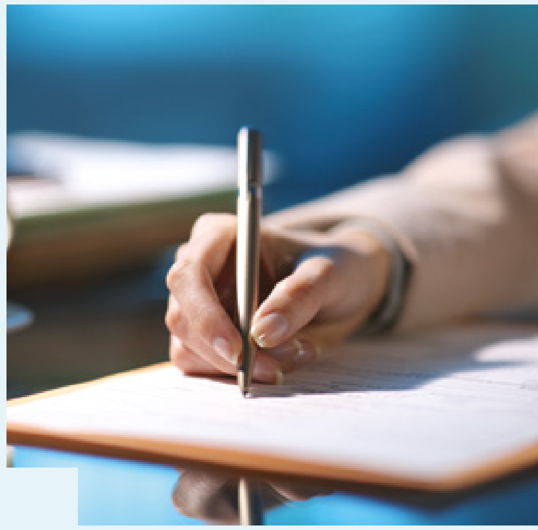
When interviewed, participants agreed overall that exercise after stoma surgery is a good thing. They felt the abdominal exercises were beneficial for improving their physical fitness, preventing hernias, improving their balance, and enhancing their overall wellbeing. Some said they had initially anticipated exercising would be painful but were relieved to find it wasn't. However, others voiced concerns that abdominal exercises could cause their stoma to rupture, separate from the skin, or be pushed in. Participants also felt uneasy trying exercises too soon, and suggested that 2–3 weeks after surgery might be a good time to start.

Many people felt they needed help and guidance on getting started with abdominal exercises, as well as reassurance the exercises were safe. They suggested that stoma-specific exercise classes would be something they'd find useful.

It seems, then, that abdominal exercise after stoma surgery can potentially be beneficial. However, we must acknowledge that this study was carried out with a small group of people, and other ostomates may have different experiences. We also need to know more about the positive and negative effects of these types of exercises, so further research on this topic would be useful. Whilst this research might help you in making decisions about exercise after surgery, it's important to always seek advice from your consultant or health professional before beginning any new exercise regime.

STUDY 3

My third selection was a systematic review conducted by a group of researchers in the UK.



This is a careful search of all the published articles on a topic and a summary of their findings. The review explored the effect having a stoma has on the physical function of people aged 60 and over. The researchers were also interested in the impact on their quality of life.

The authors found 857 potentially relevant articles published between 2001 and 2021. By reading through the titles and then the abstracts, they were able to reduce this to 25 articles containing useful information. These articles reported studies from several different countries, and, in total, included 6,972 patients. The researchers assessed how good the articles were using a 'quality appraisal' checklist, and found them to be mostly of either good or fair quality.

When looking at the evidence from the 25 studies, the researchers found having a stoma was associated with worsening physical function and quality of life for people in this age group. Reasons put forward included that older people were less likely to seek help for stoma complications such as skin irritation and leakage, or difficulties adapting to living with a stoma. This, in turn, led them to have worse quality of life and physical function. Another explanation suggested was that some older individuals may find daily stoma care more challenging due to the physical changes that come with age.

These findings give quite a negative impression of the impact of stoma surgery on the lives of people aged 60 and over, suggesting more support is needed to help them adapt to life after surgery. However, we know these negative effects don't apply to everyone, and that many ostomates in this age group live fulfilling lives. One thing to note from these results is that the majority of the studies in this systematic review only included people with a stoma as a result of cancer. We don't know, therefore, whether their poorer physical function and quality of life was due to the stoma, or because of other treatments or symptoms of cancer. It's important, then, that future research includes people who have a stoma for other reasons, as well as trying to distinguish the impact of cancer versus the effect of having a stoma.

STUDY 4

The final study is also UK-based, where researchers aimed to achieve consensus on the difficulties faced by people with a stoma, particularly focusing on bag leakage.

A method called the 'Delphi technique' was used, which involves individuals voting for their preferences on a particular topic, and then later having the opportunity to change their vote based on others' views.

This study involved 12 people (three with a colostomy, five a urostomy and four an ileostomy), aged between 26 and 75. Representatives from Colostomy UK, the Urostomy Association (UA), the Ileostomy and Internal Pouch Association (IA) and Coloplast, also took part. Participants were initially given statements on the following themes developed from the stoma research literature: product and fit; relationships; mental health and support; confidence; daily life; and out and about. They were then asked to give a rating indicating how strongly they agreed with each statement. A meeting was then held between the three charities (Colostomy UK, UA, IA) and Coloplast, to look at these ratings and agree on a 'Call to Action', which highlighted key areas for improving stoma care.

Participants agreed that stoma-related problems, particularly leakage, can significantly affect people's social and professional lives, causing physical and mental health difficulties. The 'Call to Action' comprised a number of recommendations, including:

- Delivery of individualised and holistic care is fundamental for people with stomas
- Positive education is needed throughout the healthcare service to understand how stomas affect people
- To reduce the impact of leakage and its complications, and improve quality of life, healthcare professionals should have access to information on product innovations
- Lifelong support and engagement from stoma care nurses is important to reduce leakage
- Ostomates should be offered an annual review that includes mental health, skin health and product choice
- Ostomates need access to mental health support
- Employers must be aware of, and educated on, how to support ostomates

The researchers concluded that more effort is required to ensure the needs of ostomates are met, and that everyone has equal access to specialist stoma care and support.

This study fed into the finalised 'Call to Action' that was recently shared by Colostomy UK in the UK Parliament. This is a big step in the right direction, which it's hoped can improve the care and support routinely provided to ostomates.

Aibibula M, Burry G, Gagen G et al. (2022) Gaining consensus: the challenges of living with a stoma and the impact of stoma leakage. British Journal of Nursing, 31(6): S30-S39.

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Neuberger L, Braude P, Weeks K et al. (2022). A new stoma for an older person – An association with quality of life and physical function: A systematic review. Journal of the American Geriatrics Society, https://doi.org/10.1111/jgs.17803.

Christmas cards

Spread the festive cheer this winter with our Colostomy UK Christmas cards. These biodegradable cards picture a quintessentially English village snow scene, with a classic red post box and robin. The message inside reads "With best wishes for Christmas and the New Year". Our cards come in packs of 10 and 100% of profits from every purchase goes towards helping ostomates.

So, make someone feel special this Christmas by sending them a handwritten card and support Colostomy UK at the same time.

Order form

Colostomy UK Christmas Cards (pack of 10 biodegradable cards with envelopes) £4.50

Postage and packaging

Please add the following contribution for card orders of:

Orders up to £5 - £1.50
Orders between £5.01 & £10.00 - £2.95
Orders between £10.01 & £20.00 - £3.75
Orders between £20.01 & £50.00 - £4.95
Orders in excess of £50.00 - £6.50

Number of Packs

Sub Total - £ ______

UK P&P - £ ______

Donation (optional) - £ ______

TOTAL - £ ______

Personal details

Title: ______
Name: ______
Tel: ______
Email: ______

Address: ______
______
______ Postcode: ______

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

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

Paying by cheque

Cheques should be made payable to Colostomy UK and sent to:

Colostomy UK, PO Box 280, Weston super Mare,
North Somerset BS22 9ZD

Paying by card

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

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

Signed: ______ Dated: ______

Gift Aid Statement:
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 purchase 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.

Colostomy UK

volunteers

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

A message from Max:

Our volunteers answer the Stoma Helpline after 5pm on weekdays (and sometimes during the day) and all day and all night on weekends and bank holidays. Research shows that experience-based support (e.g. ostomate to ostomate) is very effective.

In simple terms, having been through stoma surgery and experienced life afterwards, puts our helpliners in a unique position to empathise, support and advise others in a similar situation. Indeed, our charity was founded on this principle in 1967.

We also know that calling a helpline takes courage. People worry about things like: Who will answer? Will they understand me and be able to help? Will I be wasting their time?

With this in mind, I asked some of our helpline volunteers to say something about themselves and talk about the calls we receive.

Hi, I'm Bobbie

A long-standing volunteer recounts having the line one Christmas Day.

I have been a helpline volunteer for 10 years now. I have two stomas myself. One Christmas Day when I wasn't with my offspring, my husband and I played golf. It's the one day of the year when there are so few people on the course, I am able to keep my phone on. So, I was trying to line up a putt and my phone goes off, making me jump and miss the hole (much to my husband's delight). I spoke to the caller and asked them if they could quickly tee off, then as I walked along the fairway, I was able to advise them on stopping bag leaks! A bit of an extreme example I know, but hopefully it will help readers understand we are normal and do all the usual things like dealing with children, cooking, watching tv, playing sports etc.

Hi, I'm Christine

Does four hours a week during the day (Mon or Tues).

Although I'm retired, I have a busy life, with a husband, children, grandchildren… I do lots of cooking, gardening, singing with local groups, reading, decorating, puzzles etc. I also do admin work for the voluntary services department at our hospital.

In March 2021 I had an urgent colostomy after finding a large rectal tumour. It wasn't the best time, but life goes on, and I was determined to get on with mine. Searching the web, I discovered Colostomy UK in the two weeks between diagnosis and surgery, and immediately registered.

Earlier this year, I thought, “Why don't I volunteer? If I can help a few people, even in a small way, I should do so.”

I've been doing my weekly slot for a few months and have had varied calls – I'm always amazed at people's different experiences. There have been a few calls which made me sad, but more where the caller and I have had a few chuckles and a good old chinwag. At the end of each session, I feel like I've made some people feel more positive, and better informed.

Hi, I'm Dawn

Joined the team in February this year

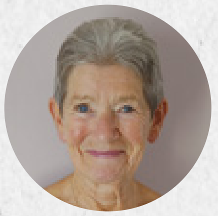
I'm aged 56 and married, hopefully due to become a granny this November, administrator to a group of seven churches, church warden and newbie Colostomy UK helpline volunteer.

I suffered Crohn's for twenty years before having an ileostomy in 2013. I then had my rectum removed in 2018 due to cancer. Post-op has been amazing, no more Crohn's, cancer gone, no pain, no rectal discharge, just nothing but feeling better, no medication, no hospital appointments, no more dreading bathroom disasters every time I left the house. I am truly blessed and have been given a great new life, so I decided it was time to try and do something, so here I am!

Volunteering on the helpline is a gift, it helps me feel that all that time of illness had a reward. I can share my personal experiences and knowledge and hopefully help others feel a little easier about their own situations. I get to chat to all ages and stages of illness. I learn more and more each time and all the while am supported by a great office team and band of volunteers.

After online training, completing the dreaded safeguarding course and DBS procedure I was ready to sign up for some helpline shifts. The first two sessions, calls zero! It can happen and then you get an afternoon of back-to-back calls. Every call is different: some people need leaflets, some reassurance, some to be advised that medical assistance is required. It's that random, but always with the comfort of knowing that the team are there in the background.

You can sign up for one shift, ten shifts, you can split shifts and if you can't make a shift, there is no problem. Lack of knowledge and medical detail is not a barrier: we listen, refer, signpost, reassure and advise. We are not and are not meant to be medical experts!



Hi, I'm Sally

A long-standing volunteer, takes the line alternate Saturdays.

Here are calls received during a recent one:

9.30am Caller calling on behalf of wife – needs advice, 15 minutes.

11.30am Caller's supplier let him down – advice, 10 minutes.

12.45pm Regular caller, complex, 35 minutes.

1pm Unused medical supplies – signposted caller to two charities who could take them, 5 minutes.

3pm Elderly caller needing advice and reassurance – 20 minutes, this lady wanted to talk.

3.35pm Female caller, helped her before, wanted to give an update, 30 minutes.

4pm This is the time we normally eat on Saturday, leave the oven on just in case my meal needs warming and it usually does, think the record is four times, it happens (thankfully not today, yippee).

8pm Male caller, complex call, needed reassurance regarding forthcoming surgery – 45 minutes.

10pm(ish) Bedtime, phone at the ready for quick exit from bed (and no I don't stay up all night waiting for it to ring), fingers crossed and relax!

Is that a typical Saturday? There is no such thing! Call intake can range from two to 15 and anywhere in between. Calls during unsocial hours are few and far between. The Saturday slot suits my life perfectly.

If you would like to find out about volunteering for Colostomy UK, please get in touch. And remember, volunteering doesn't have to be an onerous commitment. It's about what works for you. Maybe you can spare a couple of evenings each month or the odd weekend to take calls on our Stoma Helpline, or perhaps you have some IT or design skills that you are happy to volunteer for specific projects… Either way, I can't wait to hear from you.

Max

Endometriosis and an Emergency Stoma:

Kathryn's Story

BY RICHARD BIDDLE

Endometriosis is a condition where cells similar to those in the lining of the womb are found elsewhere in the body (such as the ovaries and fallopian tubes). Each month these cells react in the same way to those in the womb, building up and then breaking down and bleeding. Unlike cells in the womb that leave the body as a period, this blood has no way to escape. (Endometriosis UK)

Kathryn Watson is one of around 1.5 million women in the UK with endometriosis. Its causes are unknown and there is no cure. Endometriosis costs the UK economy £8.2bn p.a. in treatment, loss of work and healthcare costs. Yet, remarkably, it is only recently that the condition has been spoken about beyond the circles of those most affected. Its symptoms include painful periods, chronic pelvic pain, chronic fatigue, abnormal bleeding, back, leg, and chest pain, and infertility.

Treatment includes taking oral medicines and in severe cases, such as Kathryn's, surgery. With the latter, stoma surgery is sometimes necessary if the endometriosis has compromised the bowel and/or bladder or if either are damaged during surgery. Kathryn's story shines a light on this important area of women's health and on the more general ordeal of having an emergency stoma.

Kathryn, who is now 38, has suffered with endometriosis since she was a child. Her period pains were so excruciating she remembers one time rolling on the floor in agony, telling her mum she thought she had an appendicitis. Delays in receiving an endometriosis diagnosis are common. It is often misdiagnosed as IBS. Kathryn didn't receive her diagnosis until she was 23. Since then, she has had four lots of surgery. After the third (2017), the endometriosis grew back so quickly and strongly Kathryn was told nothing more could be done. The hospital didn't want to do a hysterectomy (which can help symptoms) as Kathryn hadn't had children.

With endometriosis having blighted her life since childhood, Kathryn refused to believe this was the end. To do so would have been to resign herself to an existence characterised by unrelenting pain. It would have meant normalising the depression and anxiety that had limited her for so long. It would have meant accepting defeat in her battle with weight, caused by years of taking hormonal drugs. Days out would continue to be cancelled and returning to Old Trafford to see her beloved Manchester United would remain nothing but a dream. The stakes were high. Motivated by what would be lost, Kathryn researched her options. One name kept coming up: Mr Phillips, an endometriosis specialist at Castle Hill Hospital, Hull. Her next battle was to get a referral. Initially her GP was reluctant, because of Kathryn's weight. But eventually her persistence (which entailed asking her GP on numerous occasions) paid off.

Kathryn visited Mr Phillips in March 2020. It was a watershed moment. Instead of fighting to be understood, she found him finishing sentences for her. He also introduced her to Tammy, an endometriosis nurse. Tammy understood how serious the condition was and, since this first meeting, has become an important source of female support for Kathryn, whose mother died when she was 17. Following this first consultation, Kathryn was booked in for further surgery in June 2020.

Covid delayed this until September 2021, when Kathryn returned to Castle Hill and was put on a false menopause. This makes the ovaries and womb smaller, making surgery easier.

> Kathryn's surgery was longer than anticipated as it was discovered that the endometriosis had completely stuck together her bladder and bowel. Her fallopian tubes were also twisted.

When she came round, Tammy explained to her that she would no longer be able to have children. Even though Kathryn knew this was a possibility, she was still devastated. News of this nature is hard to bear at the best times, but even more so when you are physically and mentally empty after major surgery.

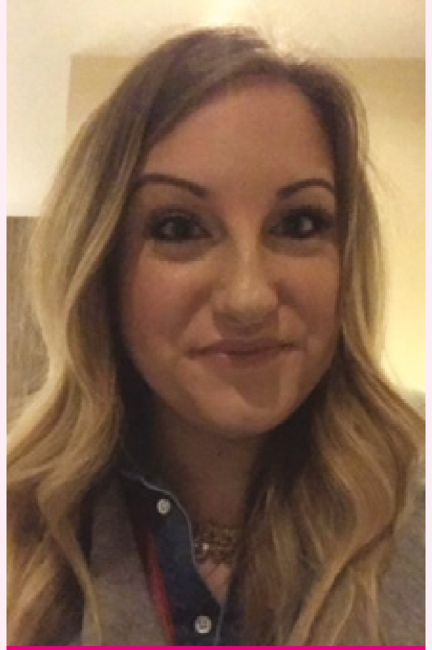
Five days later, Kathryn's body started to shut down. Her memory of this period is hazy and with no-one permitted to visit her because of covid restrictions she has nobody to tell her exactly what happened. She recollects a surgeon explaining her bowel had collapsed during surgery and that he needed to perform urgent key-hole surgery to give her a stoma. She remembers thinking her time was up and pleading with him not to. Later, after a stoma care nurse had marked her up, she was told it was to be open surgery. Fear then gripped: fear of what might happen and the fear that comes from knowing you are going to have a stoma, but don't really know what a stoma is. It had been mentioned before the endometriosis surgery as a possible complication, but understandably Kathryn's attention had been on the surgery, not what might go wrong.

When Kathryn was transferred to the high dependency ward days later, she still didn't know what a stoma was, or that she needed to empty her bag. A few nights in, her bag exploded, waking her up. Confused, upset, and humiliated, a male and female nurse stripped her off and washed her down. The day after the stoma nurse came and changed her bag. Having been through two major surgeries in almost as many days, Kathryn wasn't ready to look at her stoma. My feeling is that Kathryn was let down: surely she should have been moved to a colorectal ward after her stoma surgery? Or, if this wasn't possible logistically or for clinical reasons, then arrangements should have been made for prompt attendance by a stoma care nurse. Instances like these may be isolated, but rest assured, in Colostomy UK's capacity as advocates for ostomates we feed these things back. Unsurprisingly, Kathryn's introduction to her stoma was marred by this incident and did little to help her learn about her stoma. Eventually, the knowledge that she would have to in order to get home won over; ten days after her surgery she looked at her stoma for the first time.

Kathryn had a difficult hospital stay, both physically and mentally. The latter wasn't helped by covid restrictions. Her time on the ward coincided with the anniversary of her mother's death. She remembers crying quietly in her bed that day, wishing her dad could just come and take her home. Kathryn was discharged after three weeks, tired and three stone lighter. The day she arrived home her period started. This was the first one she had had in three years (due to having a coil). It continued for six weeks, which made the whole post-op period more challenging, particularly as her wounds prevented her showering for some weeks.

Kathryn's physical recovery proceeded as expected but mentally she struggled. Kathryn was discharged without any dietary guidance and so had to find out the hard way what she could eat. Many healthy foods didn't agree with her ileostomy. Other foods she loved were off the menu too. This led to weight gain, which Kathryn struggled with. As a beauty blogger, being unable to wear certain clothes hit her hard, denting her confidence and self-esteem, both of which were already at a low ebb. I can't help but think that the societal pressure put on young women to 'look' a certain way and conform with ideals of female beauty, can hinder their recovery after stoma surgery. It's for this reason that images such as the one we recently featured of Stoma Squad on the front cover of Tidings (spring 2022) are so important to share.

A month or so into her recovery, Kathryn began to research about stomas and how people with them overcame life's challenges as an ostomate. While doing this that she came across the Colostomy UK website and, through this, discovered a stoma support group in her area. At first she was unsure, but after checking out their Facebook page and speaking to the lady who runs the group, she decided to attend one of the monthly meetings. In many respects this proved to be a turning point for Kathryn, who by the May of this year, despite hearing in March that her bowel had healed and a reversal was possible, was put on increased medication for anxiety and depression.



> Arriving at the meeting shy and not knowing what to expect, she found a group of warm and welcoming people, and has been attending ever since. Kathryn says that for her, it was about belonging. It was about being with people who understood and could help. Through attending meetings she has learned about the bewildering array of stoma products available.

Kathryn's journey is not over, but she is headed in the right direction. She has even started to go out on day trips with friends. Happily too, when I spoke to her in the autumn she confirmed that the reversal surgery had been done and was successful. However, having gone through what she did, when she did, has had its consequences. With the various surgeries Kathryn has been unable to work. Her mental recovery is still ongoing. She also has to come to terms with the fact that she cannot have children.

Overall though, she is now in a better place than she was when she received the news back in 2017 that there was nothing that could be done for her. As we have seen before, it pays to be persistent when you have healthcare needs. Kathryn's story also illustrates the importance of support when you are unwell. It is perhaps helpful to think in terms of building your support team. Kathryn's comprises her father and friends, the people at her support group and also Tammy, her endometriosis nurse. In other words she can access peer-to-peer support, female support and also healthcare support.

I'm sure all readers hope that Kathryn goes to see the Red Devils again soon. I'm also sure that less readers will want them to win the premiership!

dear dietitian

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It can be difficult to know how to manage your stoma during the Christmas period. The festive break brings with it changes to daily routines which can affect stoma function.

You may eat more and indulge in foods which are richer than normal. Meal patterns may also be irregular (such as from snacking more). When food intake increases, stoma output can increase. Different foods will also have different effects on the consistency of the stools that are produced. Foods that are high in fibre stimulate the gut and may produce more wind and looser stools as the waste passes through the gut much quicker, giving less time for the water to be reabsorbed (Lomer 2014). Some of the high fibre foods which are often consumed at Christmas include dried fruits, mince pies, nuts, and vegetables including cauliflower and brussels sprouts.

It is therefore a good idea to keep an eye on how many mince pies, dried fruit and nuts you consume, and how much Christmas pudding you have, aiming to have these foods in moderation. The increase in fibre can lead to needing to empty your stoma pouch more often in a 24-hour period. It is important to monitor your stoma to ensure it has not become high output. A high output stoma is when the small bowel output causes water, sodium and often magnesium levels to decrease. This tends to occur when the output is >1.5-2L in a 24-hour period, though this varies according to the quantity of food and drink consumed (Nightingale 2022). Symptoms of low sodium levels include lethargy and confusion, while low magnesium levels can lead to bad headaches.

Generally, people with a stoma can eat most foods in moderation, as long as the food is chewed well to support the digestion process (Cuerda 2021). But at Christmas, it's important to recognise that your stoma output may also be increased by having a lot of richer, higher fibre foods more often and in a shorter timeframe. If you are new to having a stoma it is advisable when introducing a new food to your diet to have a small portion initially such as one to two tablespoons to see what impact it has on stoma function. People vary in how they tolerate different foods and in what amounts, so you may find you can eat a handful of dried fruit with minimal issues but another person with a stoma cannot.

Certain foods may impact stoma output and function more, for example brussels sprouts are known for increasing wind and odour, other vegetables that may also have this effect are cauliflower, cabbage and broccoli. Additionally, drinks such as alcohol can also have an impact, especially gassy drinks such as beer and lager which can cause wind and lead to a looser stool output. Alongside alcohol, fizzy drinks can also impact your stoma by increasing the amount of wind passed into your pouch. To reduce this, it is recommended that you limit your intake of fizzy drinks and when drinking them let the drink stand for 10 minutes to allow some of the gas to escape. Hydration is important in managing a stoma output too. Along with the other benefits of staying hydrated, drinking enough fluids also helps to support bowel motions. It is recommended to aim for around 1500mls of fluid a day. When well hydrated urine should appear pale yellow. (To read more about stomas and hydration, see Tidings winter 2021. You can download this on the Colostomy UK website).

Alongside changes in food and drink, there can also be increased stress during the festive period. It is important to note that stress and anxiety can affect stool output. If you want to read more about the interplay between stress and your brain and your gut/digestion, then just google the 'gut-brain axis'. Therefore, it is worth considering how to reduce the impact of stress such as through meditation, yoga, and listening to calming audio.

Nightingale J M D, 'How to manage a high-output stoma', Frontline Gastroenterology 2022;13:140-151

Lomer M, Advanced nutrition and dietetics in gastroenterology: John Wiley & Sons; 2014

Cuerda C, Pironi L, Arends J, 'ESPEN practical guideline: clinical nutrition in chronic intestinal failure' Clinical Nutrition 2021; 40:(9)5196-5220

Top Tips during the festive period

- Trial new foods in small amounts and avoid foods known to cause you issues.
- Trial one or two new foods at a time and monitor your stoma.
- Chew food well and take time to eat.
- Limit intake of alcohol and fizzy drinks.
- Ensure adequate hydration, aiming for 1500mls of fluids a day.
- Try to avoid meats with gristle and cut out fatty parts.
- Peel and cook vegetables well to reduce the fibre and make them easier to digest.
- Be aware of foods which can impact on a stoma e.g. stuffing, onions, sprouts and mince pies.
- Try to have regular meal patterns.

If you have any concerns or issues about your stoma during the festive period, then contact your healthcare professional/dietitian.

Jessica's Stoma Journey: Kim Lucock

BY JILLIAN MATTHEW

You might have seen Jessica, age 8, recently on BBC Breakfast talking about her stoma and her Buttony Bear who also has a stoma. Jessica and her mum, Kim, are both passionate about raising awareness about stomas. Kim set up an online page in 2019 to help other parents with children with stomas. She said Jessica wanted to do vlogs to get her message out there. Jessica's motto is: "be brave and be positive – you can do anything you want to do with a stoma."

Jessica was born with a serious bowel problem, but it wasn't picked up in the hospital straightaway. Kim said she knew there was something wrong. It was so different from when she'd had her son six years earlier. Jessica was screaming and in pain and suffered from chronic constipation. She didn't pass the meconium (a baby's first poo) until four days later after they were back home. Kim who was 29 at the time, said it was really difficult and to see your baby have their first enema. She has been trying to get answers ever since but, so far, there is no known cause of Jessica's bowel problems. Many tests have been carried out, including biopsies. Hirschsprung's disease (where nerve cells do not develop in some parts of the bowel) has been ruled out.

Kim said when Jessica got a colostomy at age four it did make a positive difference. However, she is still unwell frequently and has had to have her stoma refashioned when it narrowed. Jessica was rushed to theatre at one point because of diversion colitis and needed medication to treat it. Diversion colitis is inflammation of the colon, and can arise as a complication of stoma surgery, any time between a month and three years afterwards. More recently she has had inflammation in her rectum causing her pain. The next step is further investigations at Great Ormond Street Hospital and Kim is hoping they will finally get some answers there. She finds it frustrating that eight years on they still do not know what the underlying cause is and that the future is still uncertain around ongoing treatment for Jessica – will she keep her stoma, or will it get reversed? Will she need to keep taking medication?

Despite this Kim and her partner keep a positive outlook. Kim said they don't wrap Jessica in cotton wool or treat her differently from their other two children. She thinks that is where Jessica gets her positive attitude from. Every child is different, but Kim believes that they can still do anything with a stoma, and they just get on with it.

Jessica loves dancing and swimming and wears crop tops with her stoma bag on show with no inhibitions. Kim just hopes she keeps that body confidence as she gets older. Jessica does get some medical anxiety; if there is a hospital visit coming up, she will worry about it. She does need to take time off school sometimes, but Kim says the teachers at her school are very good with Jessica and understanding of her situation. Although Jessica is generally open about her stoma, she was getting embarrassed at school about the pain she was having in her rectum and not saying anything. Her school came up with the idea of Jessica giving a sign that she was in pain by putting a piglet soft toy on the table.

> For stoma aware day this year, children at Jessica's school wore purple to raise awareness. Jessica has a t-shirt with a 'Be StomaAware' message.

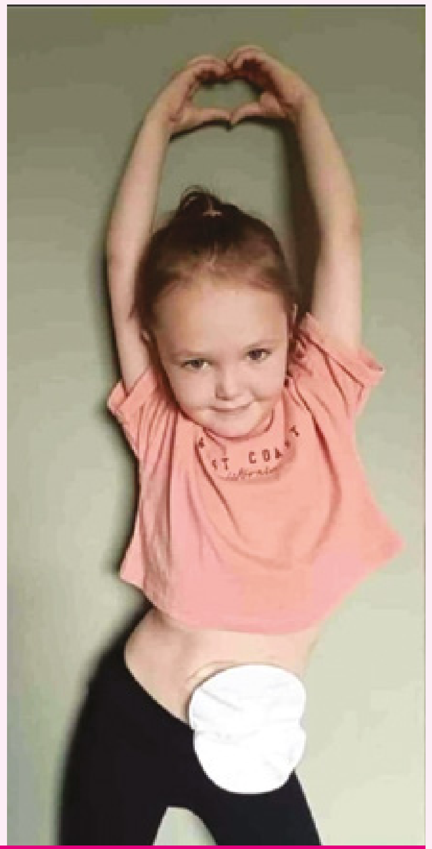
Before Jessica went into Alder Hey children's hospital in Liverpool for stoma surgery, she was given a Buttony Bear at an appointment with a nurse (you can read all about a Bear Named Buttony on pages 30-32). Kim said this made a huge difference and helped to explain things to Jessica and get her used to the idea. Jessica even came up with a name for her stoma – Apple – before her surgery. Kim herself didn't know what a stoma was and what it looked like. She found the Breakaway Foundation helpful, who support children with bowel and/or bladder diversions and dysfunctions, and their families. They explained what to expect with a stoma and showed her pictures to help her prepare so she wouldn't be seeing it for the first time on her daughter. Kim wasn't sure how Jessica would react to her stoma initially, but she looked at it straight away, which was a huge relief. She was up and walking two days later, dancing and shaking her bum!

Jessica didn't like getting her colostomy bag changed at first but was comfortable with it by the time she got home. She changes her own bag at home. She started just doing the removal spray and moved onto changing the bags herself 4-5 months later. Now Jessica doesn't want to part with her stoma and says she is keeping it forever.

A year after her getting her stoma, Jessica would take her Buttony Bear into hospital to show other children. She then started to raise money for Buttony Bears for Alder Hey hospital and she takes them into the hospital before her appointments so that children can have one before their surgery. Kim thinks it's something they will keep doing for the foreseeable future. Jessica has now raised over £20,000 for A Bear Named Buttony. Jessica received a British Citizen Award at the Palace of Westminster in October for her extraordinary fundraising efforts and stoma awareness.

Kim said she set up Jessica's stoma story page in 2019 because there wasn't much support out there for people in a similar situation, although there is a lot more now, with more and more people sharing their experiences on social media. They get messages from people all over the world about how Jessica's videos help other children. They are careful about protecting Jessica's dignity and don't show her stoma online or any distressing pictures. Kim says there is a lot of support available now and no one should be alone. She said she has used the Colostomy UK helpline for advice.

Jessica adores Adele Roberts, the Radio 1 DJ who has been sharing her stoma story. Adele has talked about Jessica being an inspiration to other young people and has said she would love to meet Jessica. Kim is organising for them to meet and hoping that will happen soon. At Colostomy UK we hope it does too, we can't wait to hear how it goes and see the pictures afterwards!



> Jessica has now raised over £20,000 for A Bear Named Buttony. Jessica received a British Citizen Award at the Palace of Westminster in October for her extraordinary fundraising efforts and stoma awareness.

A Bear Named Buttony: Jenny Gow

BY JILLIAN MATTHEW

Jenny Gow, age 51, lives in Aberdeenshire, Scotland. She works part-time as an admin assistant in a secondary school as well as part-time in hospitality and much of the rest of her time is taken up with the charity she founded – A Bear Named Buttony (www.buttonybear.com). Jenny's daughter, Eilidh, now 24, has had a stoma from age 3, and was the inspiration for setting up the charity.

The motility nerves in Eilidh's gut that help to move food and waste through the bowel did not develop properly and caused her issues from a young age. Jenny said it is an unusual condition and has led to many visits to hospital, surgeries, bowel washouts, and ongoing treatment. Eilidh started with an ileostomy but had lots of problems. She was then given a colostomy, which was subsequently reversed, but that didn't work either. She then went back to having an ileostomy but has ongoing challenges with it obstructing and retracting and keeps having to get her stoma refashioned.

Jenny said when her daughter first had a stoma, over 20 years ago, there was little information or support and she did a lot of research herself. She is pleased that things have vastly improved since then, but this was what drove her to set up her charity: to provide support to children and young people, and their parents, going through a similar situation. The idea of a teddy bear with a stoma came from when she took her daughter to Great Ormond Street Hospital. A friend had sewn a button on the bear in the same position as Eilidh's ACE. It really helped Eilidh to see the bear being just the same as her.

Jenny set up A Bear Named Buttony in 2015. She had some prior experience of charity work from being a trustee of a children's charity. The charity has grown rapidly since then, from three volunteers to 60 and a board of 12 trustees, including Jenny. Initially the charity operated under the Breakaway Foundation but decided in 2019 to stand on their own feet. It has now been an independent registered charity for three years.

Since starting, a total of 4,700 bears have been provided to children having stoma surgery. The charity also provides wash bags to young adults up to the age of 25, which contain pouch covers, a radar key and toiletries. These are sent to the hospital to be handed out before they have surgery. Bears are sometimes sent to adults before surgery to help their child get used to them having a stoma. They have also just started providing a urology pack to children who need to self catharise.

> Since starting, a total of 4,700 bears have been provided to children having stoma surgery.

Although A Bear Named Buttony has grown over the years, it's still very much a family affair. Jenny is the one who buys the bears and attaches a fabric stoma to each one with her friend Lynn who designed the stoma attachment. Her husband posts them from their small village post office. The book that now accompanies the bears was written by a mum of a child who had received a bear, and it was illustrated by one of Jenny's daughter's friends. Jenny said, "Buttony is all over the house!". There is a real community spirit too living in a village, with many local people getting involved and helping to fundraise or volunteer.

As well as providing the bears and washbags, Buttony has active social media accounts, Jenny said they try to keep it positive. They don't offer advice but will lend an ear to parents who are going through a tough time. She will often signpost people to other charities to get more clinical advice, including Colostomy UK. Jenny said she has used the Colostomy UK helpline herself in the past. Families often keep in touch with Jenny and she has become friends with some of the people they have helped over the years. They have the mum of the child who received the first bear when Buttony was launched in 2015 on the charity's board of trustees.

Jessica (of Jessica's stoma story see pages 26-28) received a Buttony Bear when she was in Alder Hey children's hospital in Liverpool. Jessica and her mum Kim got in touch with Jenny because they wanted to sponsor a bear themselves and do more to help other children. Now Jessica fundraises for all the Buttony Bears supplied to Alder Hey and raises awareness for the charity. Jenny said that Jessica has a fantastic attitude and is setting a great example for other children going through a similar experience. She's also helping to combat the stigma around stomas more generally.

Jenny thinks awareness around stomas has hugely improved and that people are happier to speak about bowels and poo. She thinks it is definitely heading the right way but there can still be a negative slant in the media. She also said that some medical staff still apologise if you need a stoma, which can set a negative tone from the beginning rather than promote the benefits it will bring.

Jenny's daughter Eilidh, who makes short films for the BBC, still has problems with her bowel but remains positive and does what she can to raise awareness and that you can do pretty much anything with a stoma. She made a video – "Being honest about life with a stoma" – which has had over nine million views (**www.bbc.co.uk/programmes/p06sbrt3**). Awareness raising is an important part of the charity too. Jenny and other board members speak at events, although Jenny said she is quite happy to leave the public speaking to other people!

If you want to find out more about A Bear Named Buttony, then visit their website **www.buttonybear.com**. You can also contact them by email **info@buttonybear.org.uk** or by phone: **07813 720963**.

Colostomy Irrigation and You DVD

Order Form Colostomy Irrigation and you (Patients)

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

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

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

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

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

Halfx3 10v00r00 DVD Patients order form | Date of Publication: December 2020 | Copyright ©2018-2020 Colostomy UK | Registered charity no.1113471

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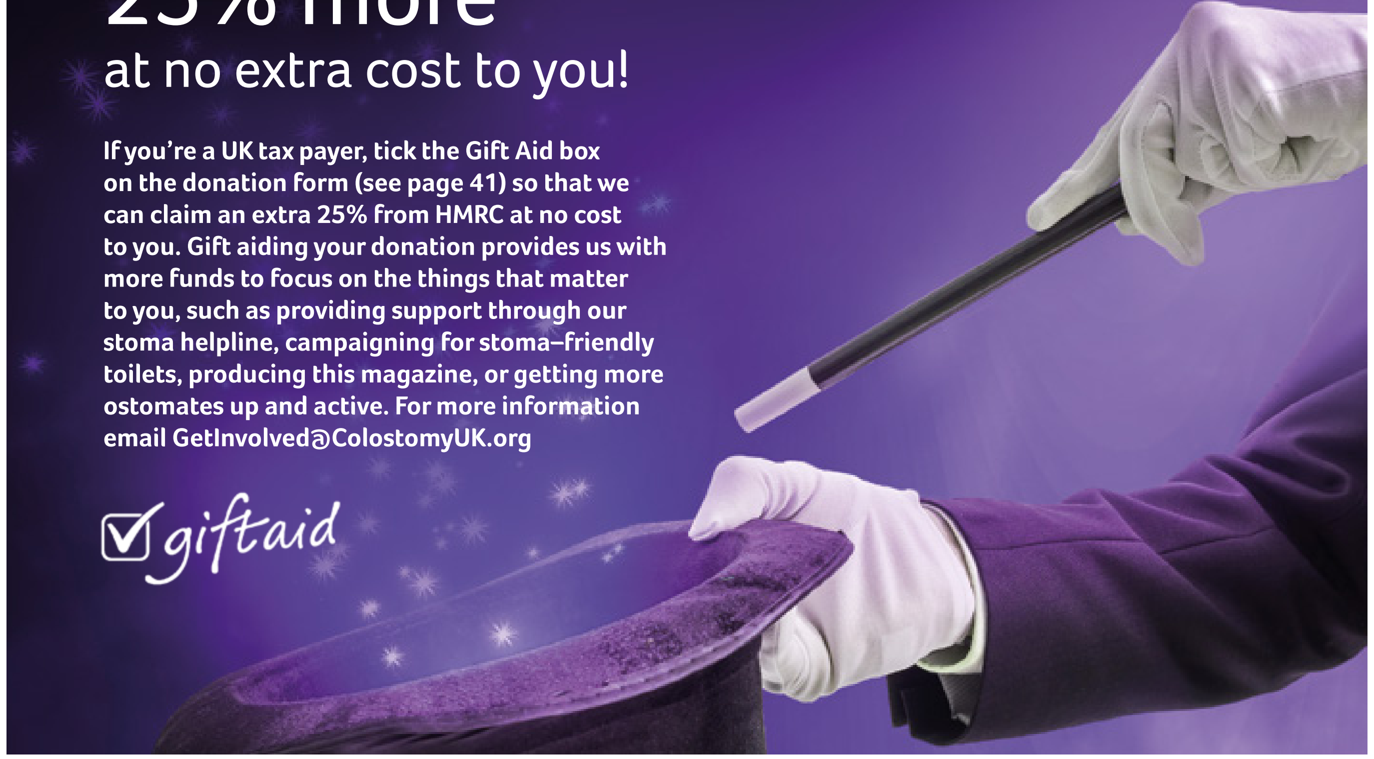

Colostomy UK

#ActiveOstomates

active ostomates®

Giovanni Cinque
Fundraising & Campaigns Manager
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Chris's Step Up For Stomas Challenge

By the time you read this our Step Up For Stomas Challenge will have finished. You can read more about it in our fundraising section. While the main aim was to raise funds for Colostomy UK, it was also about encouraging people to get active again after surgery: people like Chris, who shares his story here.

Chris still struggles with aspects of life with a stoma, but after nine years with Jim, as he's named his stoma, he feels more able to talk about his experiences.

He first suffered from symptoms of bleeding and discomfort in his teens but was too embarrassed to say anything to anyone, even his mother. The situation eased and Chris got on with his life until the mid-1990s when the symptoms returned with a vengeance.

Diagnosed with colitis, he then found himself in hospital for two weeks at a time over several years as different drugs were tried.

> *"In November 2013 I was admitted to the Great Western Hospital," says Chris. "It was to be a temporary stay with a new drug trial but then my consultant informed me that the medication was not working and furthermore, I had a perforated bowel.*

I was told I would be in theatre the following morning. If not I wouldn't see Christmas. I was so shocked and overwhelmed I burst into tears.

I had my large bowel removed and a stoma fitted and was in hospital for eight weeks and lost two stone into the bargain! I was still getting painful symptoms though over the following year, so I had to have another operation to remove the remainder of my colon.

> *Having a stoma changed my life forever. I respect my stoma (nicknamed Jim) because without him I wouldn't be here, but it is a phase in my life that changed everything. My family still treat me the same, but my lifestyle is not the same. I don't like to be too far from home whereas before we loved to travel.*

In the night, your stoma keeps working; it doesn't go to sleep – so my nights are disturbed wondering what my bag is doing."

The worst thing for 71-year-old Chris though is the discomfort he feels with clothing because of where his stoma is situated. He has had to put suits to one side and favours dungarees over trousers with a waistband.

Chris also suffers from type 2 diabetes due to the steroids that he was taking for six months prior to his surgery.

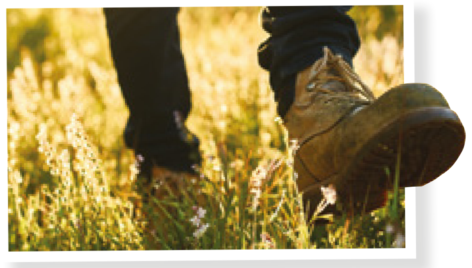
"I have had 'Jim' for coming on nine years and he can still catch me unawares! However, I am grateful to him because without him I would not be here now and would not be able to join in with social occasions with friends and family, and for that I will be forever thankful."

Chris now finds it easier to talk about his situation and is keen to raise awareness of the work of Colostomy UK.

> *"At 71, I still like to feel needed and have a purpose, so Step Up For Stomas helps me with that.*

"The Grand Avenue is three miles end to end, six miles there and back, which takes me two hours to do, and I will be doing 39 lengths. I have made a start, but the total will be 117 miles plus.

"The road has inclines, which you notice when you are walking. I meet a lot of people along the way, often with dogs in tow (or vice versa).



"Last week, mid-morning, I got talking to two women and I was wearing my Step Up For Stomas 39-challenge t-shirt. They asked me about it, and I explained I was raising funds for Colostomy UK."

Ever prepared, Chris had made up some of his business cards including his JustGiving link reference. He had them with him in his rucksack in the hope that he would meet people who would be interested and may support him. He was more than happy to dispense a card to each of the women after they had asked if he would note down his fundraising page for them!

If you're looking to return to being active after stoma surgery, why not pick up a copy of our 'Sport and Fitness after stoma surgery' booklet? It is full of great tips for exercises you can do at home, and advice around how you can get back to playing team and individual sports. It also has details of some of the great community activities we provide.

If you would like us to send you a copy, please email **hello@colostomyuk.org** or call us on **0118 939 1537**. You can also download a copy at **www.ColostomyUK.org**

Team Colostomy UK update

It's been another successful period for our Rugby League team since the summer edition of Tidings.

In July we competed in the London 9's in Chiswick alongside a variety of teams of differing abilities. Our group saw us come up against the national teams of Albania and Norway, plus Welsh side The Bangor Buffaloes. Though exhausted and a bit battered and bruised by the end of it, the day was an amazing experience; after all it's not often you can say you've played against one national team, let alone two!

We followed that up with a game against old friends Chorley Panthers. A big crowd was on hand to watch an entertaining game full of tries and big tackles. We were delighted to welcome England and Leigh Centurions star Josh Charnley, and Widnes Vikings Owen Farnworth to the game.

It was great to have two new ostomates join us on the pitch at Chorley; both Jamie Womersley and Martin Coates had a great day, with Jamie's story being picked up by his local press. This is what he had to say:

> *"It felt great to get back into rugby and I would definitely advise people with a stoma to play more sports. I'm really grateful to Colostomy UK, I didn't think I'd ever be in a playing environment at rugby again, but they made it possible."*

Our last outing of 2022 takes place after we go to print. Excitingly we will be part of the Rugby League World Cup opening weekend in October, where we'll be taking part in the Squads on the Tyne Festival before Italy play Scotland at Kingston Park. The World Cup starts twenty-four hours earlier when England play Samoa at St James's Park.

It's also been a time to celebrate some amazing achievements from our players away from Team Colostomy UK. Firstly, huge congratulations to Tom Kaye and Ryan Owens (pictured) whose Leeds Rhinos Physical Disability Rugby League team was crowned 2022 champions, with Ryan scoring the winning try in extra time! A big well done too to Alex Hounsell and Sion Wright who were selected to play for West Wales in the end of season 'Origin' series, and this in their first season of Rugby League!

Colostomy UK #StomaAware

campaigns

Libby Herbert
CEO
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Colostomy UK Scores a Slam-Dunk at World Club Basketball Tournament

Last year's autumn edition of Tidings featured Eric Douglin's story. To recap, Eric had an emergency stoma in January 2021 after diverticulitis caused a tear in his intestine. He then went on to develop sepsis and catch Covid-19. If that wasn't bad enough, like many others at the time, Eric also had to endure a lonely hospital stay because of the restrictions on visiting in place during lockdown. Post-op, Eric struggled to come to terms with his stoma and with what had happened to him. Aside from his family and friends, one thing that helped him recover was his love of basketball, which brings me to this article.

Eric is the founder of the World Club Basketball Tournament. This year the tourney ran for the first time since the pandemic. In September teams from across the world descended on Summerfields Leisure Centre in Hastings to duke it out for the title and showcase how basketball, and sport in general, has the power to unite people from different backgrounds and cultures. We were delighted when Eric asked Colostomy UK to attend as a chosen charity, along with Kidney Research UK.

At this point, you may be wondering why, as a charity that supports people with stomas, we would be so keen to attend? Put simply, it's all about spreading awareness: awareness of what we do; awareness of what a stoma is; and awareness of the challenges that people with stomas face in their daily lives. Events like this give us a platform. They are an opportunity to get the stoma message out to a wider audience. Our belief is that the more we do this, the quicker we will break down the stigma that still surrounds having a stoma in some areas of society. We're under no illusions. We know this is going to take time and lots of effort, but it's a central plank of our StomaAware campaign (click the campaigns tab on our website to find out more).

Libby Herbert (CEO), Maxyne McGinley (Volunteers & Community Manager) and CUK volunteer Angela Dolan went on our behalf and enjoyed two action-packed days of basketball. It was a well-attended competition opened by the Mayor and Deputy Mayor of Hastings. Initially players and spectators were curious about why Colostomy UK was there. This was, of course, exactly what we wanted from the event, as it provided the perfect opportunity for us to tell people! For those who we didn't get a chance to speak to, all became clear in Eric's closing speech, when he bravely told people about what he had been through recently. His tears were met by a huge round of applause and a nod to Colostomy UK from everyone in the room. What was also important from our point of view, was the media coverage the event attracted. This included Libby doing an interview with the local BBC and a report appearing on Baller TV, which is one of the USA's top media outlets.

Fundraising

Colostomy UK

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Create an Account, and go to:

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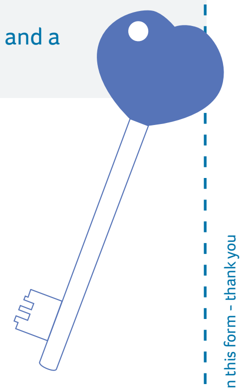
When you want to shop on Amazon, visit Amazon Smile instead, **and raise funds for Colostomy UK.**

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

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

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



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

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Name: ______________________ ______________________
Tel: ______________________ ______________________
Email: ______________________ Postcode: ______________________

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

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

Please **tick** as appropriate:

☐ I would like to receive a Radar Key for £4.50 (inc. postage and packing).

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

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

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

fundraising

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

Supporting Colostomy UK

Every month dozens of people hold events, take on challenges, or ask for donations to support Colostomy UK. As a self-funding charity, we rely on this help. Without it, we wouldn't be able to support people with stomas in nearly as many ways as we do.

Please consider raising funds for Colostomy UK, and don't worry - you don't need to even think about running a marathon or swimming 5K if you don't want to! There are loads of other ways to fundraise. You could host a coffee morning or a cake sale, or perhaps run a quiz night.

Visit **www.colostomyuk.org/get-involved/fundraising** for details of how you can make a difference. Every £1 you give really does help!

Thank You!

We don't have the space here to personally thank everyone who has supported us recently, but we'd like to give a shout out to the following individuals and organisations:

James Oldfield (pictured) raised over £400 from cutting his beard off, Lizzie Whitchurch raised a whopping £3878 from her birthday celebrations, Jessica Logan donated £75 from her Making the Invisible Visible fundraising, Moira and Chris Hammond donated £130 following the party for their Diamond Anniversary and Chorley Panthers raffle and auction after our Rugby League game raised £875.

Thanks also to the Shanly Foundation, Tay Charitable Trust, James Roll Charitable Trust, Ganzon Charitable Trust, and Banham Charitable Foundation for supporting both our core activities and our campaigns.

Clothing Collections

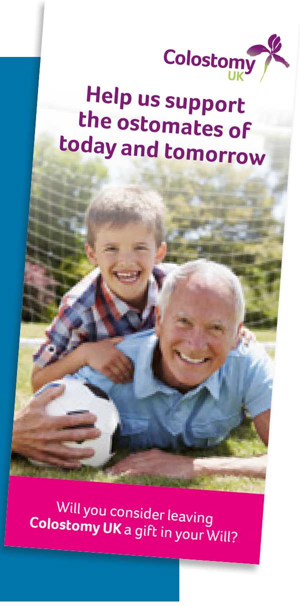
Thank you to everyone who donated their unwanted clothing and other items to Colostomy UK through our partnership with ICollect Clothes.

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

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

Legacy

Leaving a gift in your will to Colostomy UK will make a real difference to the support we are able to give to the ostomates of today and tomorrow. If you'd like further details of leaving a gift to us Please email: hello@ColostomyUK.org



Dan's the Man!

Dan Callaghan was one of tens of thousands of people who competed in the Great North Run this September.

Though you wouldn't think it to look at Dan, the run represented a very real challenge for him. One he took up to support Colostomy UK, raising nearly £1,000 so far!

So how did he go?

"It was tough, tougher than I gave it credit for and if I could give anyone one piece of advice it would be to give this run the respect it deserves and make sure you are well prepared.

> *Of course I trained, then was pulled back with injury/illness and in truth probably could have pulled out. But that "ego" I always mention wouldn't ever let me do that, I fight every day so one more wasn't going to hurt (this hurts a lot) and the bottom line here is… I started and I finished.*

I'm currently sat nursing some sunburn, bleeding foot, scraped thighs and cramped up legs. My stomach decided to bring itself to the party around the halfway point but thankfully backed off and allowed me to get on"

What led to Dan taking on the Great North Run?

> *"Anyone who knows me, is well aware that I am NOT built to run, so I wanted to take on a challenge far outside of my comfort zone, while supporting Colostomy UK"*

Speaking to Dan he revealed his teens and early twenties were not the happiest of times, but marred with ill health which left him with a frail physic and a lack of confidence. After struggling for months with debilitating symptoms, he was eventually diagnosed with colitis and was prescribed medication.

Dan then described to me getting caught out in extreme winter weather one evening in November 2004 during a taxi strike and having to walk home in the snow and bitter cold.

Over the days that followed his health deteriorated rapidly, and he was admitted to hospital.

> *"For days and days, I got progressively worse. My mental stability was gone I was just a bag of bones lying on a bed waiting to die," he said.*

Finally, as his condition became critical, in January 2005, he was wheeled into theatre for emergency stoma surgery. The operation was not a panacea though:

> *"I did not have the best of experiences for a few years managing my stoma. I still had a badly infected colon and was not well at all. My colitis was still unmanageable, and the medications made me violently sick.*
>
> *"I was still in a lot of pain, significant enough to prevent a normal life."*

But, two years after his initial surgery, aged 24, Dan elected to have the stoma made permanent. He has now had an ileostomy for 17 years.

He kept the fact quiet for a long time. It was a private thing. Gradually Dan's confidence grew, and he was able to share his situation with other people.

During the lockdown Dan, who is an area sales manager in the health and secure sector, created his own home gym and qualified as a personal trainer. He now uses his Instagram account to actively encourage fitness within the stoma community. He recently devised training plans for three people and a diet plan for another – all ostomates!

We're delighted that Dan chose to run for Colostomy UK and are proud that he plans to continue to be involved with us. Just like in 2021 he took part in our Stoma Aware day activity this year. His enthusiasm for the campaign was evident on his Instagram feed where photos of family, friends and colleagues supporting our campaign are peppered throughout the month.

For his next challenge Dan is looking forward to playing Rugby League for Team Colostomy UK!

If you would like to support Dan, his Great North Run Fundraising page is still open: **www.justgiving.com/fundraising/Danny-Callaghan7**

For information about our Stoma Aware campaign visit: **www.colostomyuk.org/campaigns**

Colostomy UK

Please support Colostomy UK

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

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Are you: ☐ An ostomate ☐ A carer ☐ A healthcare professional ☐ Family or friend
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Any other details you would like to share with us

Data Protection: Colostomy UK is registered under the The Data Protection Act 2018. The data we hold is managed in strict accordance with the Act. We do not disclose any information supplied by you to any third party organisations. (However, we may send you their promotional information, which we think may be beneficial.)

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

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Signed Date D D M M Y Y

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Telephone: **0118 939 1537** if you have any queries.

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Service User Number

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Please pay Charities Aid Foundation Direct Debits from the account detailed in this Instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this Instruction may remain with Charities Aid Foundation and, if so, details will be passed electronically to my Bank/Building Society.

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Date (DD/MM/YYYY)

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

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

Your Letters and Emails

Editor's note:

Thank you to everyone who has dropped me a line. Many of you responded to last edition's letter on airports. Although I haven't included this correspondence below, being able to share customers experiences with the airports concerned is a vital part of our ongoing work in this area.

Dear Editor,

I had a colostomy last summer, and while I can't say it's no trouble all the time, most of the time I hardly know I have it – as evidenced by my grandson bouncing on me.

When people ask me how it is, I reply that having a bag is a convenient way of dealing with an inconvenient matter.

I should like to take this opportunity of thanking the NHS staff of Salisbury Hospital and district nurses who provided outstanding care. I have had many occasions to reflect on what the costs of my investigations, operations and ongoing supplies would have been without a state health service – even if I had had sufficient insurance cover. Certainly towards £80,000, with continuing supplies at £4-500 per month.
I would just say, do not believe politicians who offer you tax cuts and a fully functional NHS. The level of increased funding the NHS needs to continue to deliver effective services is totally incompatible with reducing government income, especially in a time of dramatic inflation.

Yours, M M S

From the editor - I spotted this in the Colostomy UK private Facebook group. Many people replied to the post, sharing similarly positive experiences with TUI. It shows how worthwhile it can be talking to your travel agent about your needs before you travel.

TRAVEL INFO

Hi my people,

Just letting anyone unaware know - I've just called TUI to ask for extra hand luggage allowance for my stoma supplies. The lovely lady granted it immediately and also offered to book our plane seats by a toilet, there and back. She also offered to pop a note over to our hotel, to ask for an extra lidded bin for my bag changes.

Emily

Dear Tidings,

Stoma-Friendly Toilets / Accessible Toilets

I wanted to point out that the needs of ostomates with mobility issues also need to be considered.

I have had a urostomy since my teens and have now undergone surgery to form a colostomy. I have mobility and balance issues and use a three-wheeled walker to get around. I also have to say that before I had the colostomy, when I had to change my urostomy pouch in an accessible public toilet I just managed as best as I could, often having to balance things on my walker, the sink, or my knees.

Due to my specific mobility issues I need to sit on the toilet to change my pouches, so a shelf accessible near the toilet at sitting height would make the task much easier. This would also probably need to be on both sides. I also understand that it cannot block access to any pull-down rails.

I work three days for the local council and really had to fight to get a proper disposal bin for my incontinence pads. It took a very senior manager to intervene to get a bin, which is a nappy bin. I will be interested to hear what Colostomy UK sees as a suitable disposal bin.

Another bug-bear of mine is the fact that a lot of public toilets have the baby change facilities for mothers and children in the accessible toilets - I really feel they need to be separated.

I welcome your thoughts on the above and look forward to hearing from you soon.

Thanks, L Scrase

Colostomy UK's view is a standard sanitary disposal bin (as found in public toilets) is fine.

Dear Colostomates,

I wonder how many of you with a descending colostomy - (end colostomy) have thought of using the Assura Coloplast Plug - it is a great device if your stoma is fairly predictable, a morning routine and not too much more until the evening.

It is like a tampon on a base plate and is inserted into the stoma and sticks in place, so there is no outline and you cannot feel it when correctly inserted. Initially, one would only use it for a short time but as the bowel becomes tolerant it can stay there for several hours (but not overnight). It is really useful if you irrigate.

As it is flat on the body, it is fabulous for swimming and makes changing in and out of a swimming costume in communal changing areas much easier. It looks like a sticking plaster when in place – very discreet.

Your stoma nurse would need to teach you to use it in the first instance, but you can find information about it online.

Give it a try.

Moira Hammond

We look forward to hearing from you, our readers:

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

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

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

News from Support Groups across the UK

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

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

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

Mid Devon Ostomy Support Group

Saturday 4th February 2023.

All welcome anyone with any type of stoma. We are an informal friendly group join us for a cuppa, cake & a raffle.

Meet stoma companies and usually a stoma care nurse from the Royal Devon & Exeter Hospital.

We meet at the **Boniface Centre, Crediton 2-4pm EX17 2AH**. There is a car park at rear. The Centre is also easy to get to by bus or train.

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

Berwick Ostomy Support Group

We are a small but friendly group in Berwick-upon-Tweed.

We meet once a month, every third Thursday of the month in **The William Elder Building on Castlegate, TD15 1JT**.

We have members from both England and Scotland (which causes issues at times due to different ordering systems and products permitted!). We have had several outings courtesy of Convatec and we have a different stoma rep every month. We welcome partners as well and there is no charge.

Any queries please phone Bobbie on: **07714479320.**

Are you involved in the running of a support group?

If you are and would like to give readers an update on what you have planned for 2023, or perhaps a special event that you have coming up, then don't forget the email us details: **editor@colostomyUK.org** . If we can, we will share this in the Support Group News section of Tidings. It's a great way to reach new ostomates in your area.

Channel Islands

Guernsey

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

Jersey

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

England

Berkshire

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

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

Bristol

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

Buckinghamshire

High Wycombe Stoma Support Group
T: 0800 318965

Milton Keynes Stoma Support Group (MKSSG)
E: mkssg.sec@gmail.com

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

Cambridgeshire

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

Cheshire

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

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

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

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

Cleveland

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

Co. Durham

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

Darlington Support Group
Margaret Clothier
T: 0191 333 2184

Durham Stoma Support Group
Lynn Ridley
T: 0191 333 2184

Cornwall

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

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

Cumbria

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

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

Derbyshire

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

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

Devon

Devon IA
E: devon@iasupport.org

Mid Devon Ostomy Support Group
Janice E: 07923 975 051
E: janice234ford@gmail.com

Plymouth & District Bowel Cancer Support Group
Rita: 0785 557 1840
E: admin@plmdistbcsg.com

Dorset

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

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

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

Essex

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

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

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

Optimistic Ostomates
Angela Taylor T: 01702 385 510

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

Hampshire

Replummed Stoma Support Group
W: www.replummed.me

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

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

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

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

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

Herefordshire

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

Hertfordshire

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

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

Isle of Wight

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

Kent

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

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

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

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

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

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

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

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

Thanet Stoma Buddies Support Group
Kathy T: 01843 291 825

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

Lancashire

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

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

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

Leicestershire

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

Lincolnshire

Grantham Support Group
Bobbie/Rachel T: 01476 464 822

London

Bowel & Other Cancer Support Newham
T: 020 8553 5366

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

Newham Stoma Support Group
Lauren King T: 020 7055 5576

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

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

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

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

Merseyside

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

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

St Helens Cancer Support Group
Bob Martin T: 01744 345 365
E: contact@sthelenscancersupportgroup.org.uk

Middlesex

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

Norfolk

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

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

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

Northamptonshire

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

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull T: 07714 479 320

Hexham Ostomy Group
Marie Douglas T:07941 433 600

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

Nottinghamshire

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

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

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

Shropshire

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

Somerset

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

Staffordshire

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

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

Suffolk

East Suffolk Ostomy Group
Ian Denison T: 01473 684865

West Suffolk & District Stoma Group
Jessica Pitt (Stoma Nurse)
T: 01638 515 525

Surrey

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

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

Stoma Support Group
Robin Young T: 01428 723 255

Sussex

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

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

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

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

Tyne and Wear

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

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

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

Warwickshire

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

Wessex

Wessex Stoma Support Group
Karen Berryman
T: 01980 590 599
E: info@wessex-stoma.co.uk
W: www.wessex-stoma.co.uk

West Midlands

Coventry Stoma Support
Martin T: 07947 385 643
E: coventrystoma@btinternet.com

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

Wiltshire

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

Wessex Stoma Support Group
Karen Berryman T: 01980 590 599
E: info@wessex-stoma.co.uk
W: wessex-stoma.co.uk

Worcestershire

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

Yorkshire

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

Airedale Stoma Support
Sue Hall T: 01535 646 373

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

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

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

Bradford Stoma Support Group
Lisa Hall T: 07552 276 747

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

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

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

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

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

Second Chance Ostomy Yorkshire
Jackie Butterworth T: 07544882353
E: secondchanceostomyyorkshire@gmail.com
W: www.secondchance-ostomyyorkshire.org

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

Isle of Man

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

Northern Ireland

County Antrim

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

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

County Armagh

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

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

County Down

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

Ulster Hospital
Hazel/Martina T: 028 9055 0498

Londonderry

Causeway Support Group
Mary Kane T: 028 7034 6264

Republic of Ireland

County Mayo

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

Dublin

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

Scotland

Ayrshire

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

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

Fife

Fife Ostomy Support Group
Ishbel Barr T: 01592 772 200

Lanarkshire

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

Moray

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

Scottish Borders

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

West Lothian

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

South Lanarkshire

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

Wales

Aberystwyth

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

Bridgend

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

Carmarthenshire

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

Conwy

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

Gwent

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

Mid Glamorgan

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

Pembrokeshire

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

Powys

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

Rhondda Cynon Taf

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

Swansea

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

Colostomy UK

Our **NEW #StomaAware t-shirts** are available to buy via our shop!

Show the world that you're Stoma Aware and encourage others to be too with our brand new t-shirt.

These stylish tops are £17.99, and available in sizes **Small** to **XXL**.

The t-shirts are 100% cotton, and feature our Stoma Aware logo on the front and ColostomyUK.org on the back.

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Adjustable Hole Hernia Support Belt

Tube Hernia Support Belt With Lace

Connect with stoma nurses. Connect with community. Connect with solutions.

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- ✓ Connect with stoma nurses and product specialists
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