Summer 2022 | Issue 66

Colostomy UK

AWARD-WINNING

Tidings

Supporting & empowering ostomates

“I Only Really Told Three Friends I Had a Bag.”

TOM KAYE

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Getting Active After Surgery

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Howard Griffith: A New Chapter in Life

Real stories Real people

Colostomy UK

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Dear readers

Welcome to the summer edition of Tidings. How things have changed in the last 12 months!

Last summer, we were still occasionally queuing to get into the supermarket. The vaccination programme was in its infancy. In the press and in every home, the talk was about whether 21 June would be 'Freedom Day' or if the newly emerging Delta variant would put a halt to this (which of course it did). In my diary entry for 3 June, I noted with some concern how cases had exceeded 5,000 that day. Little did I know that they would hit 200,000 a day just over six months later.

Thankfully things now feel more normal. The Colostomy UK team is back in the office full time, which makes everything much easier for all concerned: from fulfilling requests for literature, to putting together Tidings. I am also pleased to report that we are seeing a steady resumption across the country of support group meetings, which I know so many of you have missed. Call me old fashioned, but doing these by Zoom is not the same as seeing people face to face.

There is also the very real chance that some readers will get to enjoy this edition while relaxing on holiday somewhere. Hopefully, what lies ahead won't disappoint! As I promised last time round, Dear Nurse is back, with Mark Johnson giving valuable advice about returning to being active after surgery. Kate Andrews, a postgraduate from Manchester Metropolitan University, reports on the findings of her recent study into the impact on patients of delays in elective surgery. This was research that members of the Colostomy UK private Facebook group participated in. There is also an informative piece from our volunteer Ken Edwards about the Mitrofanoff procedure, which I'm sure many people will have heard of, but won't necessarily know when it is used or what is involved.

To round things off, we have four real lives stories. At my request, John Hunter, who submitted some poems to Tidings last spring, sent me the journal he kept while he was in hospital having reversal surgery. It is a very personal account of the experience. We learn from Howard Griffith about how both he and his mother have ended up with stomas. Our final two stories touch on something I have been thinking about recently, which is how the timing of illness and resultant stoma surgery (e.g. your stage in life when it happens) can go on to have very specific consequences. Emma Hankin, who is a 32-year-old nurse, talks about the impact on her career and relationships. While Tom Kaye, who plays Rugby League for the Colostomy UK team, recounts how having a stoma as a child had implications for everything from his schoolwork to forming friendships.

I'll sign off by reminding you of our raffle and how we are doing this differently this year. Details can be found on page 19. I also need to point out that we made an error with this last time round and misquoted the amount of the 3rd place prizes. All is now correct, but obviously if you entered the draw based on what we quoted first time round, then we will be more than happy to refund you.

Best wishes,

Richard

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

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

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For a media pack and advertising rates:
0118 939 1537
Cameron Robertson
GetInvolved@ColostomyUK.org

Social media:

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

WWW.**COLOSTOMYUK**.ORG

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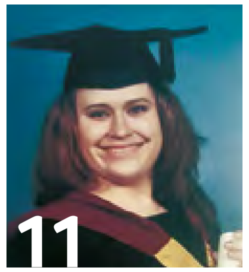
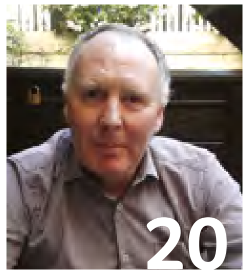
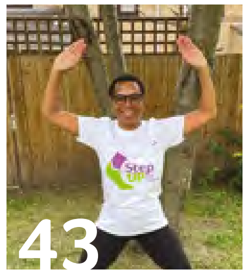






Colostomy UK News

Real Lives

Wellbeing

Fundraising

Support

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 9 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
General Manager
Libby.Herbert@ColostomyUK.org

Stoma Supplies Sent to Ukraine

We are sure that all readers have been shocked by the Russian invasion of Ukraine, worried about the plight of refugees and wondered how ostomates in particular will cope.

We are pleased to report that, thanks to the hard work of our volunteer Irene Constable, along with Rachael Griffiths of Home Instead, four pallets of stoma supplies were sent to countries bordering Ukraine who are giving sanctuary to people fleeing the country. The items were donated by ostomates in the Shropshire area having become surplus mainly because of bereavements or changes to prescriptions.

We are Out and About Again!

With face-to-face support group meetings taking place again, Cam and Giovanni from the office team were pleased to attend one held in Kent by the Ashford Stoma Support Group.

Cam only joined Colostomy UK this year and so it was a particularly worthwhile trip for him, as he got to speak with lots of people with stomas and hear first-hand about the challenges ostomates can sometimes face. Thanks to the group's organisers (inc. David Christian who is one of our volunteers), Giovanni was given the opportunity to tell the attendees about Colostomy UK, the support we offer and our current campaigns. This led to much discussion around the issue of public toilets. All in all, it was a great day out, and nice to be out and about again.

We Welcome a New Member to the Office Team

Jacqui Ramsey joined us in the spring as our new Fundraising & Communications Executive, bringing with her plenty of relevant experience and a varied range of skills.

Jacqui's career in the media has encompassed working with local BBC radio and television, as well as writing features for national magazines and newspapers.

Previously Jacqui worked as a textile conservator and restorer. She retains a passion for all things textile related and is a volunteer for The Textile Society. When time permits, she can be found stitching an item of clothing for her wardrobe. She is also frequently tempted to purchase more fabric to add to her extensive stash!

With a life-long interest in health, Jacqui enjoys yoga and walking and likes to relax by cooking up a feast to share with friends or family.

Local Campaigning Success!

We are pleased to report that Shropshire County Council have passed a unanimous motion to make all their public facilities stoma-friendly.

This came about after the consort to the Mayor of Oswestry came into contact with Irene Constable, who is a Colostomy UK volunteer and who also runs the Bums on Tums support group. Irene was able to explain how just making some very simple inexpensive changes to toilets would benefit people with stomas. Taking into account stand alone toilet facilities and those managed by the council in leisure centres, libraries and attractions such as museums, approximately 42 toilets will be upgraded.

Thank You to Everyone Who Responded

Last summer we invited readers to participate in an online survey about the companies that manufacture and deliver stoma care products. Thank you to everyone who responded.

We are now analysing and collating the results, from which we hope to build a better picture of stoma care across the UK. This in turn will help us to work with the NHS and the stoma industry.

Dear Reader,

I have lived with my stoma for nearly 13 years.

I was diagnosed with anal cancer in September 2008 and underwent chemotherapy and radiotherapy. Initially, the treatment was deemed successful but six months later, in March the following year, I was told that the cancer had returned, and the only way forward was to have a colostomy. I was also informed that the operation could not be reversed. My reaction was one of great disappointment and disbelief. Added to that was the worry that the cancer may have spread.

While in hospital for my surgery in June 2009, a stoma nurse handed me some leaflets – my first introduction to Colostomy UK. I found the literature very informative and extremely helpful.

Back at home after my op, though I'd had confirmation that the cancer had not spread, all was far from plain sailing. My confidence was destroyed completely. Eventually, I started to get out a little bit. I remember my wife taking me out for a light lunch and from then on, I started to feel a bit better, even though all the activities I'd taken for granted like going to a pub or restaurant felt like breaking new ground.

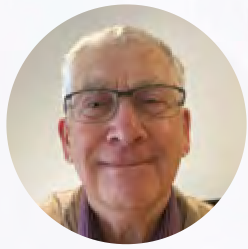
Though I am lucky to have a supportive and sympathetic wife and good friends around me, I recognised immediately the immense value the services Colostomy UK provide. Especially the helpline, to those who are not so fortunate as me and feel alone. So, towards the end of 2009, when the charity sent out a request for volunteers, I didn't hesitate to respond and offer my help.

Now 12 years on, I still get a lot of pleasure out of supporting callers who feel hopeless, helping them to see a way forward and know that they have someone to talk to. Sometimes it's a simple bit of practical advice and know-how that can transform someone's life.

It's such a surprise to many callers that we are available 24/7 and being 'live' is very much appreciated.

Colostomy UK depends on donations to keep this and their other services going, making sure that anyone affected by stoma surgery gets the support and the information they need. So, please help with a contribution if you can. However big or small it all adds up.

Best wishes,



Colin Allum

Colin Allum

Tidings

Colostomy UK

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By phone: 0118 939 1537

Online at: ColostomyUK.org

By post – using the form opposite

Please support Colostomy UK

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.

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

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Gender: ☐ Male ☐ Female ☐ Other, please specify:

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Are you: ☐ An ostomate ☐ A carer ☐ A healthcare professional ☐ Family or friend ☐ Other, please specify:

Stoma type: ☐ Colostomy ☐ Ileostomy ☐ Urostomy

Date of surgery: Reason for surgery:

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

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☐ Monthly **Colostomy UK** support e–newsletters

☐ Post from carefully selected third parties (eg about open days or offers)

☐ Emails from carefully selected third parties (eg about open days or offers)

Any other details you would like to share with us

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T66

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Life on Hold

The Consequences of Serious Illness for a Young Adult

BY RICHARD BIDDLE

Emma Hankin contacted me earlier this year keen to share her story. She felt it was important to raise awareness, both generally and within the ostomate community, that people have stomas for reasons other than bowel/bladder dysfunction or disease.

The latter did not apply to her and, somewhat irrationally, it has sometimes made her feel a bit of a fraud as a result. Like Emma, I believe the whole area warrants more profile. However, as we spoke and I delved deeper into what she had been through, it became clear that Emma's story was worth telling for other reasons too. It illustrates how, as a patient, it is vital to be persistent when you know things are wrong, even if this contradicts the views of those charged with treating you. It also highlights how serious illness and stoma surgery can have different consequences depending on how old you are, or what life stage you are at, when they happen.

What Emma describes as her 'nightmare' began in October 2012 when she was 22 years old and training to be a nurse. It began with a pain in her groin area. Scans were done, along with an ultrasound. This revealed an enlarged lymph node, but no further action was taken as it was put down to fibromyalgia, which Emma suffers from. Four months after this episode, Emma completed her studies and qualified as a nurse.

As you can imagine, Emma was thrilled at her achievement and looking forward to getting on in nursing. Sadly, the excitement was short lived. A few months later Emma slipped in the bath. At the time it seemed innocuous. Emma thought she had just bruised her coccyx. Instead, it turned out to be the next steps on a dark road that threatened to dash all her hopes and dreams. As Emma navigated its twists and turns she contemplated suicide, but eventually found salvation, when having stoma surgery gave her the strength to rebuild and re-start her life.

Emma visited her GP the day after her fall, who gave her anti-inflammatories, but these didn't help. Instead, the pain got worse, to the point where sleeping became a problem. As it was near Christmas Emma decided to put on a brave face and accompany a friend on a shopping trip, but this ended abruptly when she started to feel 'fuzzy in the head' and out of breath. That night Emma vomited profusely and by the morning she was struggling to breathe. A call to NHS 111 lead to an ambulance being called. The paramedics rushed Emma to hospital, explaining she needed to go into resus as she was at risk of cardiac arrest.

At the hospital things moved quickly. An examination of Emma's buttocks revealed redness and swelling. It was thought she had a small abscess. This was drained and Emma was moved onto the ward. Six hours later the pain was so intense she couldn't tolerate her wound being packed. Emma also became confused and started shivering uncontrollably as sepsis developed and she went into shock. More surgery followed. Emma wasn't aware until she woke hours later that this had revealed an abscess much larger than was first thought. Emma had a massive horseshoe abscess, the cavity of which was so big the surgeon said you could put both hands in and clap.

It took a three-week hospital stay for Emma to recover, after which she started her first nursing job. But before she had her feet under the table, Emma was plagued by pain. She also started to experience faecal leakage. At a post-op check-up, Emma's surgeon told her the wound was healing well. Despite these reassurances, matters did not improve. Within three months of the appointment Emma was experiencing daily leakage and could feel a 'hole' inside her when she sat down. A return visit to the surgeon didn't help. She was told all was fine and it was 'just in her head'. By this point the consequences of chronic illness were already emerging. Emma couldn't work and feared leaving the house. Her mental health spiralled downwards.

Over the next two months Emma went to A&E eight times and each time was told: 'there's nothing the matter, it's all in your head'. On her ninth visit, she was admitted with severe dehydration and on being examined, was found to have a fistula. Under normal circumstances one might be upset to discover this. For Emma it was a relief. She remembers crying with the strange elation of knowing that she wasn't crazy, she had been right all along. With treatment just around the corner Emma began to think in terms of a fresh start. Her fistulotomy took place in November, after which she successfully applied for a new nursing post. This meant sharing accommodation away from home with another nurse.

Emma started at her new hospital in January 2014, positive about what the future held and happy to consign to the past her experiences of the previous years. But just three months later, the faecal leakage began again. Bleeding also occurred as her skin began to break down. Long periods of absence from work followed. Eventually, feeling low and beaten, Emma resigned from her job and moved back home.

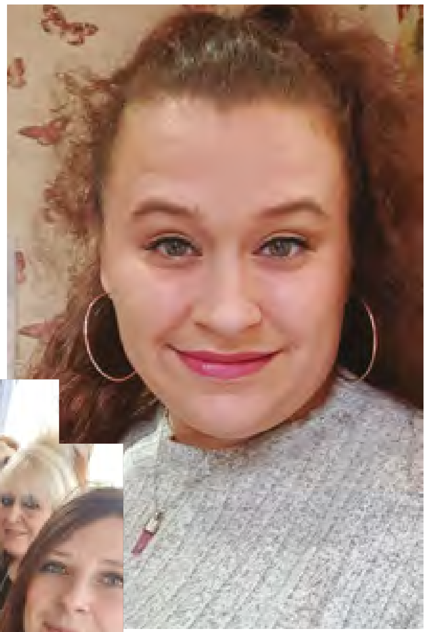
She visited her surgeon as an outpatient, who again said nothing was physically wrong with her and suggested her problems resided in the stress of working as a nurse. The implication was that she should find another career. For Emma this was the final straw. It broke her completely and she started to contemplate suicide, as she just couldn't see how she could continue living as she was. Emma also considered taking legal action, but being so low she struggled to advocate for herself and couldn't find anyone willing to take the case. Recognising how desperate she had become, her consultant referred Emma to the local crisis team, and she began group therapy, rather than wait for individual help.

Although this averted a potential disaster, it didn't solve Emma's problems. Now pretty much isolated from the outside world, Emma started to do some research. It was through doing this that she came across St Mark's Hospital, Harrow. As many readers will know, St Mark's is a specialist bowel hospital. Emma first visited her saviours, as she calls their colorectal team, in October 2014. It was immediately found that her symptoms were not the result of stress, but due to damage done to her anal sphincter.

Over the next five years, Emma's career and life in general were put on hold. Various treatments were tried including bio-feedback therapy, Botox injections, and the insertion of a Sacral Nerve Stimulator (after a long wait for funding to be approved). Ultimately though, nothing worked. Successes were always short-lived. Emma's mental health deteriorated again as she could see no end to the terrible road on which she found herself travelling. Constant pain and accidents meant long periods of absence from work. But the impacts went far beyond this. Emma could not attend social events or family gatherings and she had no relationships, sexual or otherwise.

A CT scan in April 2019 found that Emma's internal sphincter (which controls when you need to open your bowels) had detached from her anus. This had not been picked up before, because of the amount of scar tissue left from her abscess and fistula surgeries. It explained why none of the treatments had worked. It was at this point that stoma surgery was discussed. Emma begged her surgeon to proceed and in the autumn surgery for a permanent loop colostomy was scheduled for April 2020. During the interim Emma had to manually evacuate herself but was consoled by the hope that the end was now in sight. Thanks to Covid, however, this end was delayed… Emma finally had stoma surgery in November 2020.

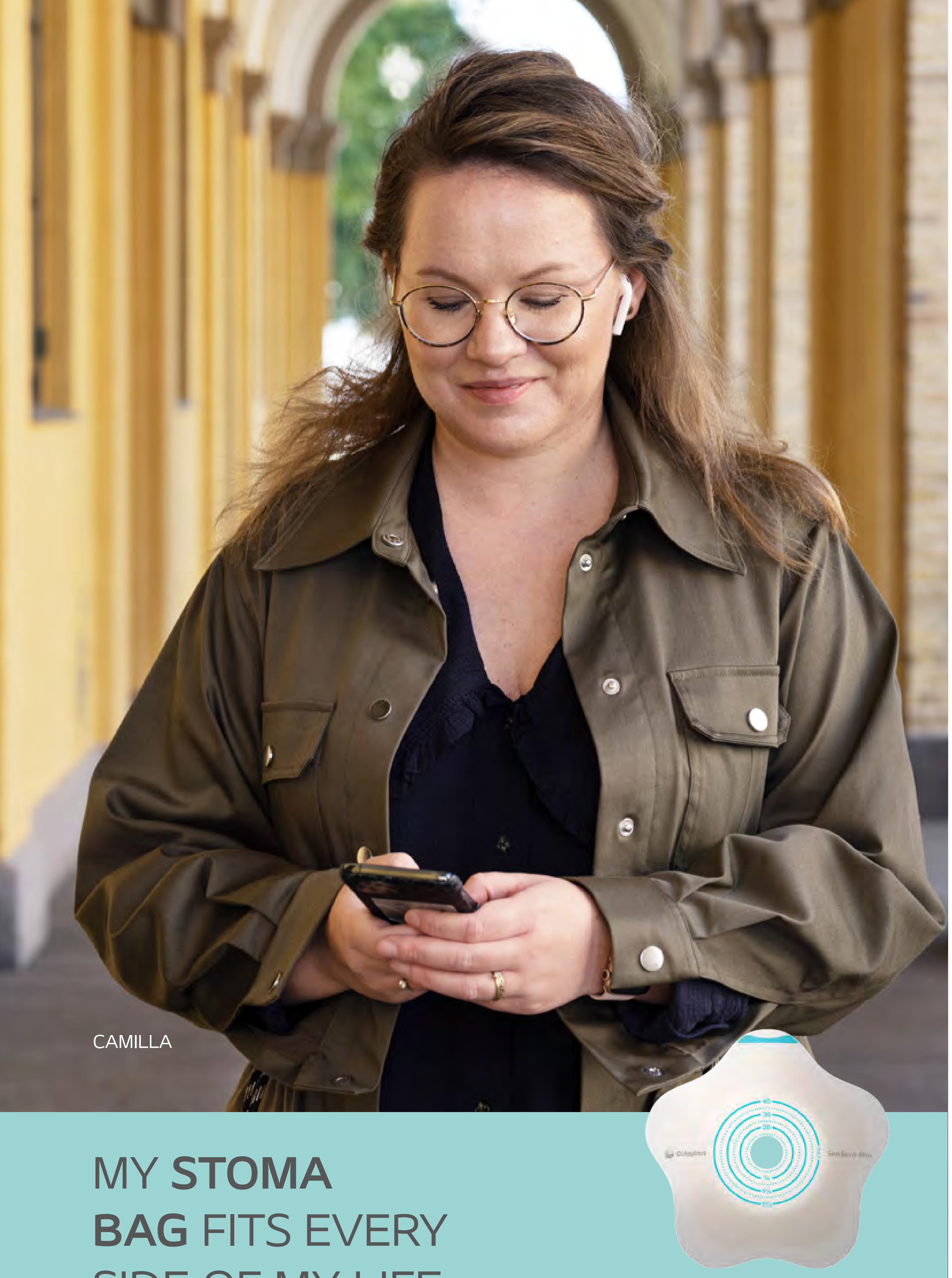
The years from your early twenties to your early thirties are important for many reasons. It's often when you forge ahead in your chosen career and embark on long-term relationships. Many people go on to marry and have children. Emma has not had a relationship now for ten years because she hasn't felt able to, and while her friends from university have gone on to become matrons, sisters and ward managers, Emma is still seen as a novice. Since 2012, she estimates having completed only three years of work. The mental toll has also been considerable. She was diagnosed last year with Complex Post-Traumatic Stress Disorder, caused by all the surgery and other interventions she has endured.



Yet, despite all this, Emma is on the up. She now has more bright than dark days. Since her stoma surgery, she has wrestled back control of her life. Her family and friends have all commented on the positive change they have seen and how the smiley young independent woman they thought they had lost, is slowly re-emerging. Emma will always bear the scars of her experiences, but she can now step back and reflect on what happened. She believes she is a better nurse for what she went through. It has helped her to see things from the patient's perspective and to recognise that physical and mental recovery are not things to be dealt with in isolation, but instead go hand in hand.

When I asked Emma what advice she would give new ostomates, or people about to have stoma surgery, or facing difficult decisions on how to proceed with their treatment, her response was the perfect end to this story:

I would advise them to go to Colostomy UK, research their surgery and utilise the Colostomy UK Stoma Helpline and the Colostomy UK private Facebook Support Group. They will support throughout. Let them be there with you and your family on your journey, don't try and do it alone. But remember you may have challenges ahead.



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"It makes me feel more secure – I feel it has the right fit to my body."

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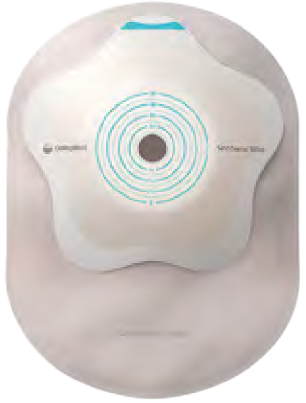
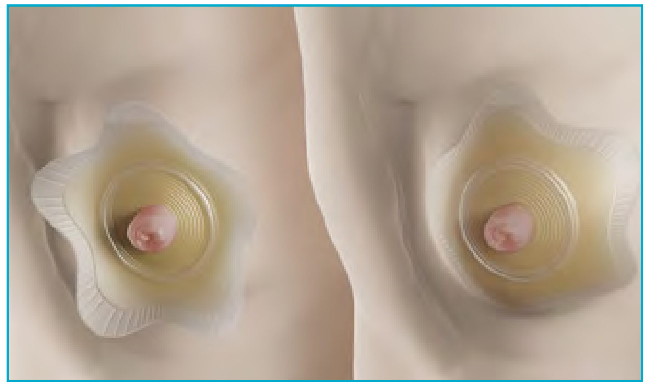
A built in stability ring supports the stoma at the centre of the baseplate while the star shape hugs the body.





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Date of Stoma Surgery ____________________

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Coloplast

dear nurse

Mark Johnson
Clinical Nurse Specialist – Stoma
Fittleworth Medical Ltd

Getting Active After Surgery

Stoma surgery can be physically, mentally and emotionally demanding, with the effects lasting for months after. So how do you return to where you were pre-surgery, how do you get your mojo back?

In this article I explore the benefits of exercise and how simple adjustments to everyday life can help get you back on track.

There is so much information available about post-operative exercise it can feel overwhelming. Exercise (like stoma surgery and recovery) is individual and as ostomates it is fine to have your own unique goals, ambitions and expectations.

Taking the first steps

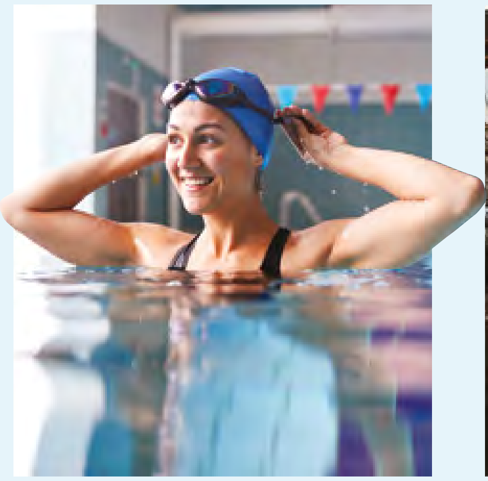
The first thing I tell new and experienced stoma patients is listen to your body. It is amazing at giving you signals. When something hurts or gives discomfort, it is your body's way of telling you it's not happy. In some instances, you can push through this, increasing the activity slightly each time to break barriers; at other times it's a solid line that shouldn't be crossed.

The second thing is to set yourself goals and achievement points. If you had never done a 5k run pre-surgery, it's unrealistic to set this as your initial goal post-surgery. Whatever your ultimate ambition or target is, break it down and set yourself little goals and little wins along the way so you can track and see your achievements. Keep a simple diary of how you are feeling and the activities you achieved that day. Then you can look back in six months' time to see how far you've come.

There are many programmes out there that support or advise on fitness, being active or returning to activity. Colostomy UK's Active Ostomates includes sessions at home, in groups and online. Fittleworth offers another programme which includes simple steps and gives pre-op and post-op advice. Just like your goals and ambitions, it is important to find the right programme for you.

Support wear

It is important with any exercises or activity to be mindful of the risk of hernia around your stoma. Building up your core muscles and breathing exercises to engage these core muscles can be helpful. But having support wear in the form of a belt or other support is often advisable. You should speak to your stoma care nurse for further information.



Where to start

If you are starting from a place of physical fitness pre-surgery, then returning to exercise is easier. Remember to build up slowly and, as above, listen to your body. If you are starting from scratch (or wanting to try something new) then there are several activities that are good for building up or as a gentle start:

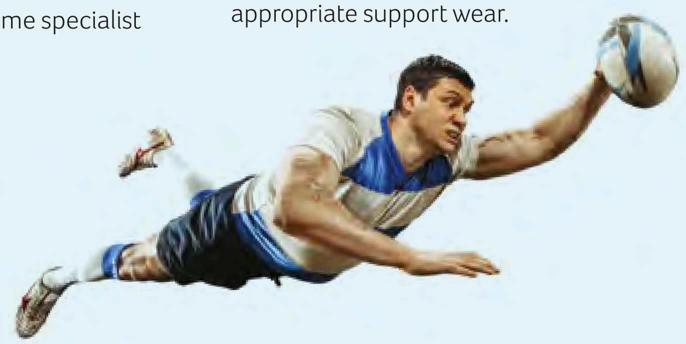
Swimming: is an amazing way to gently exercise. You can do it at your pace and time. There are lots of support groups or swimming clubs that run appointment based or limited participant sessions to help build confidence in yourself and in your stoma pouch. My advice is to do some googling and see what you have local to you. Colostomy UK may also be able to help with this.

It may also be possible to use a cap or mini stoma pouch to maximise discretion. Your stoma care nurse can advise. You could also visit the various manufacturers' websites. Ostomy garment manufacturers are worth a look too, as some specialist swim wear is available.

Pilates/yoga: one of the limiting factors to exercise and feeling well post-surgery can be stretching and moving freely. This can be helped by basic and gentle yoga or Pilates, both of which are available in classes (some are free). There are also free videos and guides online that enable you to do Pilates/yoga at home. Colostomy UK also run these classes through support groups, see pages 52-53 for further details.

Bike riding: slightly more intense (or can be), but again a great exercise that is easy to get into and continue at your own pace. This is a perfect example of where goal setting works well and where you will start to see a real difference in fitness and ability.

Where to finish…Contact sports: I've added in contact sports to show that there is no limit to the physical activities an ostomate can take part in. A little planning and a little confidence and you will be off! But… please speak to your stoma care nurse beforehand for advice regarding guards for your stoma and/or appropriate support wear.



The next steps in your journey

Being active post stoma surgery is equally as important as the rest of your recovery. Being active also helps your overall recovery. For some, stoma surgery was forced upon them as a result of a sudden life event, for others stoma surgery can be a means to getting their life back after a limiting condition. For whatever reason your stoma was formed, I encourage you to embrace it, learn to live with it and return to the life that you wish to have, not the life that you feel might be imposed on you because you now have a stoma.

There is lots of support and advice out there to help you on your journey, in the form of booklets, the internet, podcasts and social media. Remember too, that fellow ostomates can also help. I urge you to use it, enhance your life with a stoma and find the new you!

For your free copy please contact: **hello@ColostomyUK.org** or alternatively visit our website and download a copy.

Colostomy UK | Annual Prize Draw

Dear Reader

In past years your copy of Tidings included a book of raffle tickets for our annual prize draw.

The amount raised each year from the prize draw makes a significant difference to Colostomy UK and helps to run our support services including our stoma helpline and produce this magazine.

We are running the draw as usual this year but in a slightly different way. Rather than having a book of tickets, we are using the entry form you can see on the opposite page.

To enter the prize draw you just need to complete the form, selecting the number of entries you would like to buy (each one costs £1), and then return it to us with your payment.

Your unique draw numbers will be allocated to you on receipt of your entry. Let us know if you would like to receive an email confirming these.

So why are we changing things?

Quite simply, it's to reduce costs so that more goes towards supporting the ostomate community. With the old way of doing things we had to pay to produce the raffle tickets. There was also an insertion fee for the magazine. Changing to the new way of doing things removes both these costs!

If you have any queries, please email **GetInvolved@ColostomyUK.org**

Colostomy UK

Would you like **more**?

More news from Colostomy UK direct to your inbox.

More information about the latest stoma product updates.

More opportunities to take part in surveys and have your say on the future of stoma care in the UK.

More access to our support literature and factsheets about all aspects of living with a stoma.

Get more from Colostomy UK by signing up to receive our monthly e-newsletters.
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Colostomy UK

WIN BIG with the Colostomy UK annual prize draw!

£1 PER ENTRY

1st Prize	2nd Prize	3rd Prize
£2,500	£1,000	10 x £100

1. My Tickets

I would like to buy: ☐ 5 ☐ 10 ☐ Other: ______ entries* at £1 each £ ______

I would like to make an additional donation of... £ ______

*Please note, you can only have a maximum of 30 entries per raffle.

Total amount enclosed: £ ______

2. My Details

Title*: ______ First name*: ______ Last name*: ______

Address*: ______

Postcode*: ______ Phone Number: ______

Email*: ______ Date of birth: ______

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.)

3. My Payment

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

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

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

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

Signed ______ Date ☐☐☐☐☐☐ (D D M M Y Y)

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You can also order your draw entries online at colostomyuk.bigcartel.com

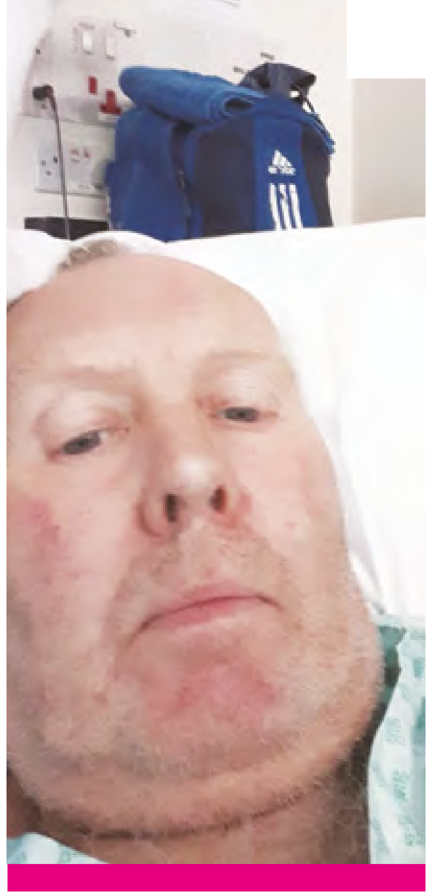
No tickets may be sold by or to anyone under 18 years. No tickets may be sold on the street. Promoter: Mr Giovanni Cinque, Colostomy UK, 100 Berkshire Place, Winnersh, Berkshire RG41 5RD. Please return no later than Friday 21 October 2022. Late entries will be treated as donations. Winning numbers will be selected by random number generator and notified by telephone, email or post and announced in the Spring 2023 edition of Tidings. Colostomy UK is a charity registered in England and Wales No: 1113471. Lottery Licence no: LOT000141

The Reverse Operation

BY JOHN HUNTER

In September 2019 a cancerous tumour was found on my bowel. Shortly after, I met the consultant. He leaned over close and said: “We’re going on a journey and I’m going to cure your cancer,” and outlined the key stages of that journey: radiotherapy, chemotherapy, stoma surgery and a reversal. From the outset, the reversal was the goal foremost in my mind.

My reversal was scheduled for January 2021, but Covid-19 led to a cancellation. Luckily Solihull Hospital became Covid-free during lockdown allowing elective surgery to restart. After several months of uncertainty, I learned mine would be on 19 April. My operation took two hours. I woke to discover all had gone well, before being conveyed to Ward 15 to eke out my recovery. The remainder of the day I spent drinking tea and getting to know the other person on the ward. After our tea-fest I felt no inclination to urinate which wasn’t unusual.



Next morning a consultant appeared. Consultants appeared at my bedside like mysterious ships in the night, vast, highly respected stately galleons of yore. Sometimes they had a flotilla of eager young yachts in tow. They never introduced themselves, so I gave them names based on their characteristics.

The first I dubbed ‘The Droll Consultant’ because of his droll sense of humour. When I asked if he had taken part in my operation he replied, “Good Lord, no! I’m just an innocent bystander.” Nothing seemed to unnerve him. Droll Consultant informed me that during surgery they discovered and repaired a parastomal hernia, which explained the minor pain I was experiencing below the wound site. He said I would be discharged after I had passed wind and made stool. In his droll laidback way, he also indicated there might be a wait, potentially up to four days. He cautioned me like some ancient prophet that the bowels, once open, would produce very loose stool and it may seem like a flood.

Nothing further happened that day; however, the fact I had not passed much urine began to concern the staff. They requested a bladder scan, which showed about 450ml of urine in my bladder. After all the tea I was neither concerned, nor surprised. I wasn’t in pain. Droll Consultant had commented that bladder scans were not very accurate and the assistant taking the scan also pointed out 450ml might only be a small percentage of the whole bladder, hence their desire to insert a catheter was thwarted.

By the third day, nursing staff were more anxious. I was confident it would come out eventually and felt no pressure to pee. However, there were also concerns that nothing was forthcoming from my bowels either. Another bladder scan was carried out and the night doctor was called. At 2.30 am my bed became the focus of a conference between Night Doctor, another junior doctor, the ward sister, and others. Night Doctor was concerned about the swelling in my stomach and concluded they needed to empty my bladder, so a catheter would be required. He also proposed a nasogastric tube (NGT) to remove some of my stomach contents, which he said would reduce the swelling.

After inserting the NGT the nurse let out a small squeal of pleasure: success, it was working. In the meantime, Night Doctor had contacted Heartlands Hospital about the swelling. They recommended a CT scan to check for a blockage, which was organised. Drips were dripping, and tubes were flowing. The crowd, delighted with their night’s work, left and I was alone, just me, my tubes and my mildly swollen gut. A sleepless night followed.

Next morning, Droll Consultant looked somewhat ‘phased’ when he saw me. His laid-back demeanour suffered a dent. He enquired what happened and where all the tubes had come from. I explained the night’s festivities. He seemed unconvinced and repeated that it can take several days for the bowel to begin working. I managed to persuade him that the NGT and catheter were not required. He agreed and both were removed.

It was now four days since I had been admitted. From literature I had read about how simple reverse operations were, I was disappointed at my progress.

That afternoon the bed rattled down the long corridors to my CT scan, banging occasionally into the doors. During this pantomime with the doors, I began to experience a strange but long-awaited-for event. My bottom began to quiver and released the tiniest breath of passing wind. Such an insignificant moment and yet so monumental! As the bed was parked outside the CT scan room the miraculous happened.

That night Droll Consultant’s prophecy became reality. It seemed to me the whole world was falling out of my bottom. My initial joy at having achieved the simple task of passing wind turned into a nightmare, as the next four nights became a veritable flood-plain of loose stool.

I was fortunate that the male nurse attending to me proved to be the embodiment of kindness. Originally from the Philippines, he had lived in Britain for many years and was bringing up his young family here. It was as if I had been adopted into his family. He took exceptional care of me; his kindness and compassion were so great that I do not think I would have made it through without him.

That first night he thoughtfully placed a commode at the end of my bed. Every thirty minutes or so I needed it. Sometimes I didn't reach it in time, and he had to clean the floor, the bed, the sheets, secure me new pyjamas and remove the liquid poo. The smell was dreadful. What perplexed me the most was where this waste was coming from. I had not eaten much.

I awoke on day five depleted and exhausted, but thankfully the speed of the output had slowed considerably. I was encouraged to try and get to the toilet some 15 meters away. The bed-curtain being removed I apologised to my ward companions – there were now four of us - who had complained about the smell, one of whom said he had never smelt anything like it since working on a farm as a boy.

Later that morning a more serious consultant appeared. I dubbed him the 'Superior Consultant': smartly dressed, with a brusque, no-nonsense air. He had a regatta of followers in tow, most of them typing ceaselessly into computers, no doubt capturing his wisdom for future ages. He tended to address them rather than me, hence the Superior tag. At times this made sense, it was a teaching hospital after all. However, I felt I had a right to some understanding of what had happened to me during the most eventful day so far.

I asked what the CT scan showed. He looked down at me rather quizzically and then as if addressing the American Seventh Fleet turned back to his flotilla and explained that the CT staff thought it had shown a blockage so had sought a surgical opinion. The surgeon was clear there was no blockage. The scan merely showed scarring or stitching where the bowel was re-joined.

On the sixth night the whole nightmare was re-enacted, with me struggling out of bed and onto the commode every twenty minutes or so. Once more, I was totally amazed at where the content was coming from as, again, I had been unable to digest more than a morsel.

Next morning, though totally exhausted, I was greeted by a small note of comfort. This was the promise of a single ensuite room. Gaining this new sense of privacy I felt free to rush to the loo as often as needed. The sister provided me with some cream as she pointed out evacuating my bowels so often might lead to soreness – which it did. The main downside of the move was the loss of my kind male nurse. I was now mainly left to my own devices, but this worked well, as I was now more aware of the nature of the beast and able to cope better with the incessant demands to poop.

On day eight, another consultant appeared. I dubbed him 'Casual Consultant' as he was dressed like a gardener and leaned against the wall as he spoke to me. He prescribed Loperamide, which he explained would slow my bowel motions down and firm up the output. It certainly helped stem the cascade of poo. I also managed to eat more than previous days and that evening spent more time in bed than previous nights.

Early on my ninth day I was visited by the 'Most Senior Consultant'. I knew this because his name badge corresponded with the name on the board above my bed. He was friendly but still business-like. While he spoke, his staff crowded round the door, pushing and shoving to get sightlines on the great man.

He dispensed the good news that, with the Loperamide working well, and my bloods and other measures being up to scratch, I could be discharged. I thanked him profusely, relieved to be finally released, nine days after my admission. That afternoon I said my goodbyes and thanks to all the staff. The sheer selflessness, kindness and compassion of these hard-working people overwhelmed me.

The reversal operation was the much sought for 'end' of my journey, but it turned out not to be the case. After being at home a few days I spoke to my consultant. His advice, coupled with other information I have read since, indicates it can take between nine and twelve months (24 by some accounts) for the bowels to establish a new routine. One key lesson is that after discharge one is very much on one's own. The guidance leaflet on recovery is so general and non-prescriptive under the mantra that 'each person will settle to their own pattern' as to be almost worthless. One has to be prepared to find one's own way and discover the practices and eating habits that best suit one's self.

Howard Griffith:

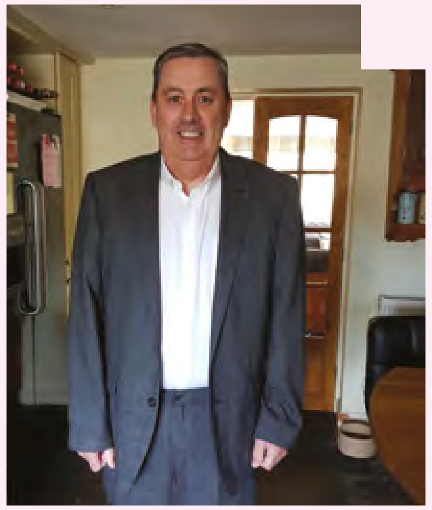
A New Chapter in Life

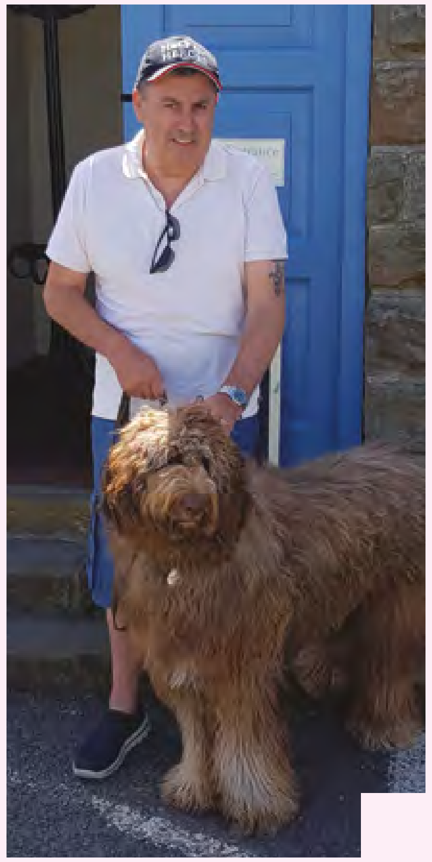
BY JILLIAN MATTHEW

Howard Griffith, a 59-year-old construction manager, grew up knowing about stomas because his mum had one. Little did he know that one day he would need one himself and with hardly any warning. However, Howard said when he was told he would need a stoma it didn't faze him at all. "I knew what a stoma bag was, it was not the end of the world. My mum has lived a full life with a stoma. Changing a bag is like changing your trousers, something you have to live with and do every day."

In late 2015, Howard had been to Cuba on holiday. He said he was feeling rough after he came home and he thought it might be food poisoning, "But then seven days later I had a bag on my side." The dates will remain ingrained in Howard's memory. He was admitted to hospital in Lincoln on 15 November 2015 and had a scan on 18 November which showed his large bowel was severely inflamed and needed urgent surgery. The likely cause was colitis or Crohn's disease. He was moved to hospital in Boston, Lincolnshire for open surgery to remove his large bowel, which took place on Saturday 22 November. Howard remembers the surgeon with a marker pen asking him where he would like his stoma. He said he wasn't that bothered at the time but wishes he'd taken more of an interest because he feels his stoma sits a bit too high on his waistline, and in hindsight, he would have chosen to have it a bit lower.

Unfortunately, Howard's surgery didn't quite go to plan, and his bowel burst while he was on the operating table. This led to sepsis, which prevented the large wound on Howard's abdomen from healing. He said it was a challenging time, but he just had to get on with it. "What choice did I have? There are a lot of people worse off than me, at least I was still here!". The sepsis meant that Howard's wound remained open; it wouldn't heal and he had a wound bag to protect it. He joked that "It was like Tesco's, I had so many bags attached to me and I had to stick my stoma bag onto my wound bag!". Following his surgery, Howard lost around seven stone in a short space of time. His body wasn't retaining nutrients. Eventually he was given feeds in hospital with the high protein content he needed. He began to put weight back on and his body started to heal. His wound finally closed in August 2016. Howard experienced problems with his rectal stump which was still intact, so he had further surgery in March 2017 to remove it. He said this was the first time he felt like he had been sewn up properly: "When I walked out of the hospital, I felt like I'd won a war on my own."





Amazingly, Howard stayed positive throughout most of his ordeal. When I asked Howard how he had coped, he said, "Smiling, I just kept smiling, and the love of the best woman in the world". When he first got home from the hospital, Howard couldn't get up the stairs, people who came to visit had to leave because of the stench from his open wound, and he suffered blowouts from his rectal stump. But his wife encouraged him to start moving and he started living life again. Once he was well enough, he started working from home, and even took his laptop into hospital when he was in for treatment. Howard said that helped him get over everything and kept his mind off things. He was in hospital for weeks at a time and they decided to get a dog. Howard felt better as it was company for his wife when he wasn't there, and good therapy for both of them while he was recovering.

Howard said it took him five years to find a bag that would stick and he frequently worried about leaks. Howard's mum was able to give him plenty of advice and support. She has had an ileostomy, same as Howard, for 50 years since the age of 32 because of colitis. Howard said they would have frequent conversations about different stoma products and his mum would also give him tips about diet. Although things have moved on a lot since his mum first had her stoma, he said he remembers his mum wearing a belt to keep her stoma bag on and rolling micropore around her tummy several times when going on a girls' night out. Howard obviously gets a lot of his resilience from his mum. She has had parastomal hernias and has recently recovered from breast cancer but she has remained positive throughout.

In 2017, two years after Howard had his initial surgery, his son was found to be carrying a gene (human leucocyte antigen B27 or HLA-B27) which can cause several autoimmune inflammatory conditions. This can include ankylosing spondylitis, psoriasis, rheumatoid arthritis and colitis. It was discovered while his son was living and working in Australia for a few years. He'd had psoriasis for many years, which affected him quite badly. During his stay he suffered an ankle injury while playing football. It wasn't getting any better and he also had a twinge in his spine, which he believed was down to limping because of his sore ankle. He sought medical advice, and the GP, upon seeing the extent of his psoriasis and problem with his spine, suspected the cause to be genetic. He arranged a blood test and Howard's son tested positive for HLA-B27. The GP asked if there was a family history of colitis and this led Howard to get tested and found he too carried the gene. His mum decided not to have the test as she felt it wouldn't make any difference to her now. Howard's son is on medication and his psoriasis has completely gone. Howard's experience is that little is known about the condition when he has spoken to his GP and stoma nurse about it. He is worried about getting arthritis and has arranged to get further tests and to see a rheumatologist privately. His mum has had rheumatoid arthritis as well as colitis and her brother had Crohn's or colitis, which he thinks is too much of a coincidence not to be linked genetically. Howard had bowel problems when he was younger and wonders whether earlier treatment would have led to a different outcome if the genetic condition had been picked up sooner.

Howard wants to share his story to give people a glimmer of hope if they find themselves in a similar situation – he almost didn't make it and wants people to know that you can get back to a full life, even if it feels unachievable or out of reach when you are at a low point. He also hopes that by sharing his family's experience of a potential genetic link it will inform others to ask questions about possible causes if they are finding it difficult to get a diagnosis. Howard also wants to emphasise that, "Having a stoma bag is not the end of your life, it's the start of a new one". He thinks back to where he was after his surgery and now he's fit and active and goes out cycling with his wife. He is about to start a new job in a senior position, which he never thought would happen at the age of 59 after everything he has been through. He says it's a new chapter in his life that he's grateful for and he wouldn't be here if it wasn't for his stoma.

"I Only Really Told Three Friends I Had a Bag"

BY RICHARD BIDDLE

For many people, having stoma surgery is something that happens to them in adulthood. This brings with it a range of challenges both before and after, such as those faced by Emma Hankin (see pp. 11-13). But what is it like to become seriously ill and go through stoma surgery as a child? How might this affect a child growing up and how might having a stoma so young go on to shape them as an adult?

Last autumn we published an article from a team of healthcare professionals based at Bristol Royal Hospital for Children, which started to answer these questions. But due to the nature of their study, which focused on the children and their parents at a particular moment in time, it couldn't reflect on the longer-term impact. Tom Kaye, who plays for Colostomy UK's Rugby League team, had his first bout of stoma surgery when he was eight years old. Now 32, Tom agreed to talk to me about his memories and experiences as a child and how he ended up playing for us.

I started by asking Tom to cast his mind back to when it all started:

"I come from a Rugby League family. Before I was born my dad played for Hunslet and Halifax. My brother Ben currently plays for Batley, having previously been with Leeds, Featherstone and London. My oldest brother has played at a good level too. As a child I enjoyed playing lots of sports, including golf and football, but not surprisingly rugby was my thing too.

I was diagnosed with colitis when I was eight years old. The school and teachers were very supportive. I remember being allowed extra time for things and being offered my own changing facilities. Unfortunately, the tablets I was on didn't work, so I had to have surgery. This happened as I was leaving primary school. It was tough and caused my family a lot of worry. The operation was massive and left me with a stoma. It was difficult dealing with it at a young age.

At secondary school I was off for weeks at a time and in a day when laptops were not readily available I often found myself behind and catching up. This didn't make learning a happy experience. I had tutors provided which helped, but of course this was always reliant on me having a good day or being well enough to work after school. My head of year and PE teacher were brilliant. I still speak with them now. The head of year allowed me to use staff toilets across the entire school and take breaks when I needed them. Unfortunately, not all the teachers were like this. Some just didn't understand (or want to understand). I hope schools are different now as this wasn't a nice experience. Looking back, I think it had an effect on my opportunities to develop myself. I am however grateful for those who stuck by me and put an arm round me when I needed it."

I asked Tom how he coped with managing his stoma and if life improved after surgery?

"Not really. I struggled with high and loose output, which led to frequent accidents, bag changes and a lack of energy. I was often too tired to do anything, which in turn led to me becoming depressed and developing anxieties over numerous things. Pre-surgery I had some control, but with the bag I didn't, and this made me feel something had been taken from me. My main struggle was mentally, as I tried to cope with lots of blockages, accidents and leaks."

As we know, your teenage years are important for reasons other than school. I asked Tom how he felt himself:

"It was difficult, because obviously I was going through puberty too. I really struggled having the bag. It affected my mental health, that's for sure. This wasn't helped because I didn't have the support or contact with other ostomates of a similar age. At this age, my impressions of my bag and what it meant to have a bag were easily influenced by others and what they said and how they acted. This went on to have an impact on me in later life."

We talked about how having a stoma had affected forming friendships and doing the sorts of things you would expect a teenage boy to do. It was a subject Tom found difficult to talk about.

"I kept myself away from people and only really told three friends I had a bag. I distanced myself from others, from girls and from role models because I was scared to trust people or tell them I had a colostomy. I was basically ashamed. I didn't seek the help I needed. It's something I regret now. I've lost some of my best years through being stubborn in this respect. When it came to doing social things, I withdrew completely. Social media wasn't as powerful then. I hope that now young people can use this to find help and support. I played golf for a short while, but my confidence never stayed with me long. I never slept over at a friend's house as I had never been able to form those sorts of friendships. Having a bag affected how I behaved and stopped me committing to things. I played outside with friends, but everything was restricted. I never accepted it and it made me depressed. Anxiety stopped me from living the same life as my friends. I spent a lot of time worrying about all the negative things that can happen when things go wrong with your stoma."

Tom had a reversal in 2006, when he was 14.

"Rather than making things better, my quality of life deteriorated further. Some years later I was diagnosed with chronic liver disease and an aspect of Crohn's. This led me to having a permanent Ileostomy in March 2017. The risks of the operation were hard for me and my family to deal with."

I asked Tom to reflect on his life as an ostomate so far and explain how he came to play for the Colostomy UK's Rugby League team and what this has meant for him.

"Just like other ostomates there are times when I find life with a stoma difficult. It puts you in some dark places. As anyone with a stoma will tell you the smallest things can have a massive effect on your wellbeing and day-to-day life. The impact on me was so great that in the early days (especially my mental health) I even fell out of love with rugby league.

Thankfully, my family were looking out for me. Back in 2017 when I was just out of hospital from my ileostomy surgery, my Mum wheel-chaired me to watch my brother play for Halifax against London at the Shay. They won 26-16 and, post-match, I was taken into the changing rooms to take part in the celebrations. It marked something of a turning point, even though I saw some things in that changing room (from Scott Murrell especially) that I couldn't escape because I was in a wheelchair. The visions still haunt me now! But the support I received from my brother and all the Halifax lads really made me love the game again.

It was after that I began following Team Colostomy UK on Twitter and was very excited to learn they had formed a rugby league team. When I saw they were coming up to Yorkshire I jumped at the chance to get involved, not just to get playing again but to represent a charity that wants to make a real difference and change the lives of people struggling with life with a stoma. Saturday 10 November 2018 is a day I will never forget. It was the day Team Colostomy UK played PDRL United at Featherstone Rovers in a Touch Rugby League challenge. It was my first game in over 12 years. It felt great despite the fact I got the smallest kit in the bag!!

Everyone was brilliant and seeing Libby, our first female player, fearlessly jumping in front of a man twice her size is a moment I will never forget. It was a great day. I had all my family there supporting me and I got to play some decent rugby. Having my brother Ben involved on the side lines was amazing. Scott Murrell also took their time out to speak to me before the game. In fact, between you and me, I think he's a little scared that I might take his place at Halifax! But, more than anything else, I proved you can achieve anything if you want it enough. Scoring would have been nice, but I just never got that lucky pass on the day.

To me, that Saturday highlights what fantastic work Colostomy UK does. It's not just the rugby either, it's all the other things they do, such as the support groups, exercise classes, tackling mental health, etc. It makes a real difference, and I am proof of that. I will never forget that day and look forward to pulling on the Team Colostomy UK shirt again."

Tom's story powerfully shows how having a stoma as a child can have far-reaching consequences at the time and in later life. I was also struck by the difficulties Tom faced connecting with people of his own age in similar situations. Hopefully, the growth of social media since Tom was a child may help. The popularity of Colostomy UK's private Facebook group is an indication of this. But the issue of support for young people with stomas and also their parents/carers – both in terms of its availability and accessibility – is an area requiring attention, which makes the study at Bristol I mentioned at the start, all the more important.

Colostomy UK

Literature range

Have you seen our extensive range of support literature? Suitable for ostomates, family members, friends, carers, and healthcare professionals. To order your complimentary copies contact us by:

Admin line: 08118 939 1537 | **Email:** hello@ColostomyUK.org | **Website:** ColostomyUK.org/information


Active Ostomates sport and fitness after stoma surgery


Campaigns and Projects Flyer

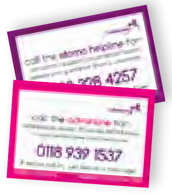

Caring for a person with a stoma


Caring for a person with a stoma and dementia

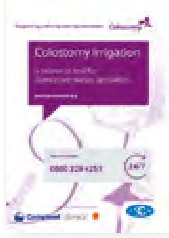

Colonoscopy through a stoma

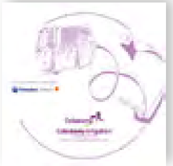

Fundraising Pack


Healthy Eating

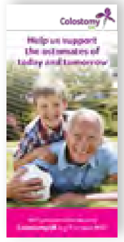

Helpline Cards


How will a stoma affect me?


Irrigation Booklet


Irrigation DVD (nurses)


Irrigation DVD (patients)


Legacy Flyer


Living with a stoma


One to one


Ovarian Cancer and stomas


Pain and discomfort

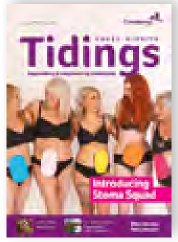

Parastomal hernias


Rectal discharge


'Sam has a stoma' colouring book

Stoma friendly toilet guideline and stickers


Stoma reversal

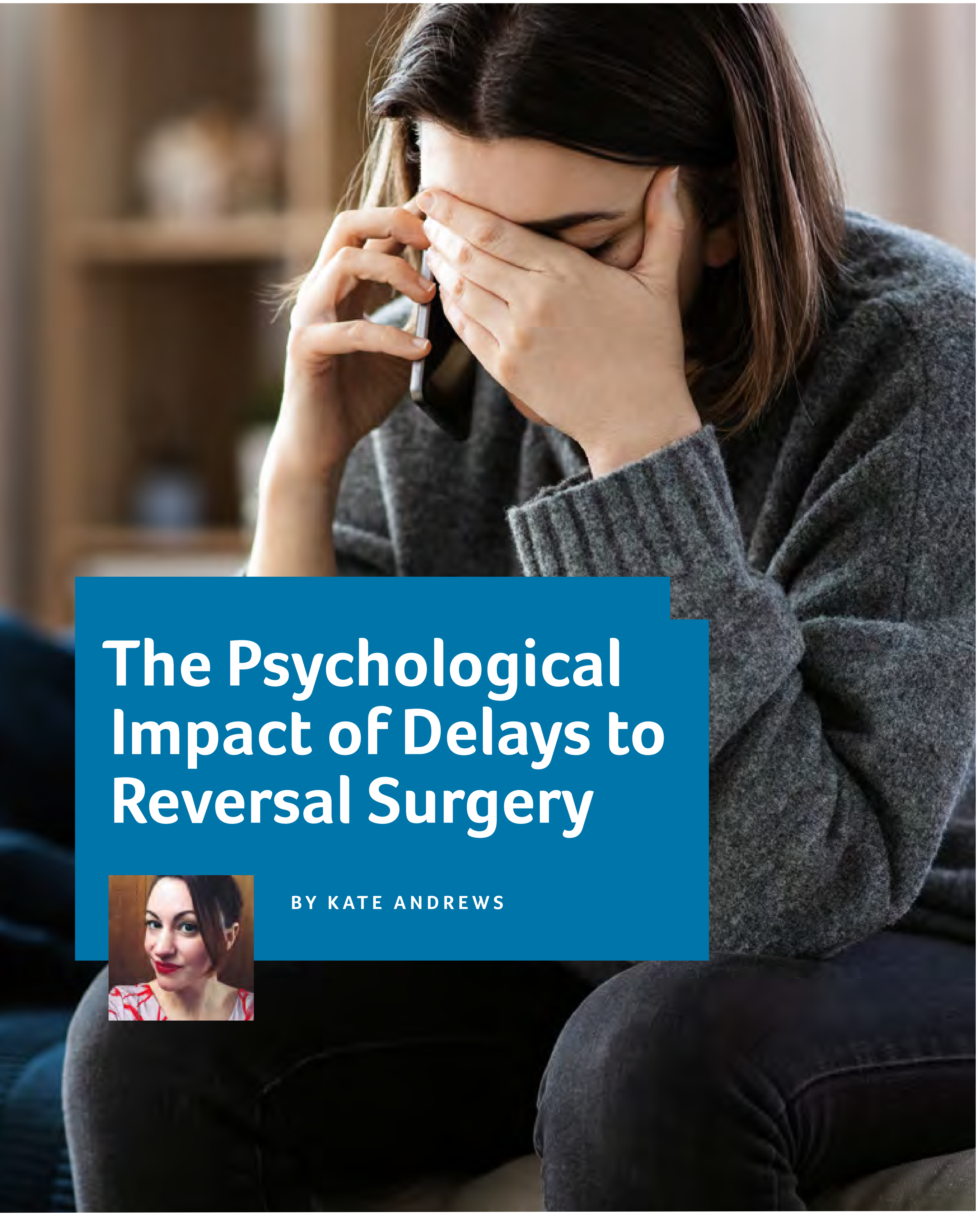

Tidings magazine


Travel advice


Travel certificate


Tri-Charity leaflet


Welcome pack



The Psychological Impact of Delays to Reversal Surgery

BY KATE ANDREWS

It will surely come as no surprise that caring for coronavirus patients in the pandemic has meant the redirection of many NHS resources to acute respiratory care, with wide-ranging implications elsewhere. Elective surgeries, including stoma reversals, seem to have been hit particularly hard. The psychological challenges and adjustments of patients living with a stoma have been researched before, but few of these studies consider the experiences of temporary ostomates; those that do report that they typically fare less well psychologically than those with a permanent stoma. The study of these patients' responses when reversal is delayed has been almost entirely absent.

In 2020 I found myself devising a subject for my Master's dissertation in psychology. My husband has a temporary stoma and had, at that time, been waiting 18 months for his reversal, with several dates proposed and then withdrawn. While he has been fortunate to live relatively comfortably with his stoma, I knew from the ostomate community that this was not the case for everyone and that the topic was ripe for exploration.

The subject area was new, so the key objective was to gather in-depth, personal accounts of lived experiences via one-to-one interview. Interviews were then manually transcribed and analysed to find recurring themes and allow comparison between participants. This is a time-consuming process and, as a lone researcher, a significant undertaking. Seven patients participated, aged between 33 and 68, with a mean age of 54. All had a temporary faecal ostomy whose reversal had been delayed; underlying diagnoses and reasons for stoma formation were varied. All participants were female, although this was by chance, rather than design. They had responded to a call for participants via the social media channels of Colostomy UK, Bowel Cancer UK and Crohn's & Colitis UK, without whose support the study would have been extremely challenging.

Interviews took place remotely over Microsoft Teams and typically lasted 45-60 minutes. Interview questions were devised in advance, but all were designed to be open and flexible, encouraging participants to share their experiences openly and allowing space to explore unanticipated topics. Each interview began with the patient describing the events that led to their stoma formation; later questions asked about topics such as their feelings about their bodies and whether they felt a good quality of life was available to them while waiting for their reversal. I was acutely aware that respondents were freely offering their time to discuss what is potentially a very upsetting topic and aimed to create a safe and supportive environment where they would be able to share freely. I disclosed my husband's status as an ostomate prior to interview, as I felt this might help participants to feel more relaxed and understood, but did not share any details of his diagnosis or reversal delay.

Analysis of interviews revealed two overarching themes – firstly, how participants felt about themselves and their bodies; and secondly, what happened when other people were involved in their lives and care. Unsurprisingly, all participants described the challenges they had faced in the aftermath of their stoma formation, and these have been explored and discussed in previous research. Particularly important in this study, however, was how participants found a need to construct a temporary identity as an ostomate and the battles of trying to accept and incorporate a bodily change that they believed would soon be reversed. For some, this temporary identity centred around their reversal, with their energies and motivations devoted to getting fit and strong for their next surgery, after which "normal life" could resume. One participant said:

> **"That's where, you know, all of my energy, my mental and physical energy, went – into getting fit for my next operation. I had overinvested, emotionally, in this six month time frame."**

Another described how her promised reversal made life bearable when she was struggling with her stoma:

> **"I didn't like dealing with it, but it was like, OK, well the worst is over, now this is where we start getting better. This is a temporary thing, so I've just got to put up with this for a little while and three months down the line it's going."**

What became extremely difficult, then, was sustaining both hope and a sense of who they were in the face of repeated delays to reversal surgery. All participants felt huge empathy with patients who were being prioritised ahead of them and many described feeling selfish when advocating for their own needs. One described calling her stoma nurse to ask when reversals might start happening again:

> **"That's when she told me that Stage 4 cancers were being picked up. You know, that's a disaster for people. I was in tears. It's like there was this wave of self-pity and then this huge humanitarian pity as well and it was all combined into a horrible mess."**

The NHS description of stoma reversal as a "lifestyle procedure" also contributed to patients feeling their needs were unimportant. Many were experiencing considerable suffering, but felt uncomfortable and even ashamed when bringing this to the attention of others. One said:

> **"If you keep phoning up, you can hear in their voices that 'Oh my god, it's her again'."**

Beyond how participants felt about their stomas and themselves was recurring discussion of their interactions with others involved in their care. While some participants had received a visit from a stoma nurse ahead of their surgery, this was not guaranteed, and those who were visited described the experience as entirely practical, with no consideration of the emotional or psychological challenges they were likely to experience. On a more positive note, several participants described the huge impact their ongoing relationship with their stoma nurse had made to their wellbeing. One described her nurse as "a guardian angel, sent from heaven", while another said:

> **"She did so much for me. She gave me back myself in pieces, as and when I could cope with them. She really, really is amazing."**

Despite these very positive experiences, participants agreed that the level of psychological support offered was extremely low, with the physical aspects of life as an ostomate always prioritised. One compared visits from her stoma nurse with postnatal care:

> **"If you compare it to when your midwife comes around, that's one of the first questions, 'How are you feeling?' And even when the stoma nurse has come round, I mean they're absolutely wonderful people, but they're looking at your stoma, they're measuring your stoma, they're checking your bags are sticking on and have you got a rash here or there or whatever. And actually, you just need someone to go, 'God, are you actually all right?'."**

Beyond their stoma nurses, participants found other healthcare professionals ill-equipped to support them. Some had experienced extremely upsetting comments, for example one participant who asked for help from a (non-stoma) nurse in hospital:

> **"I said, 'I need to change my bag in front of a nurse, to make sure I'm doing it right,' and she said, 'Well…I'll try not to be sick.'"**

Shocked, I asked how this had made her feel – she said

> **"That was horrendous."**

Most participants found that stoma-specific care had reduced dramatically during the pandemic and many had approached their GP for help. Responses were universally unhelpful, with one participant reporting that her doctor said, "Well I know nothing about stomas" and that he couldn't help her with her pain. Patients were left feeling they were a nuisance, an oddity, and had nowhere to turn. It is hardly surprising that their psychological wellbeing was reduced.

Ultimately, the majority of participants reported that they had unmet needs, many of which were psychological. This study concluded by recommending that stoma care includes much-increased psychological provision as standard, particularly after stoma formation, and that this support is structured in such a way as to empower ostomates to report their needs openly and play an active part in their care. Crucially, this support must be proactively offered and adapted when patients face delays to their reversals.

With huge thanks to the wonderfully generous and courageous participants, who shared so much with me.

Colostomy UK

volunteers

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

A message from Max:
If you have ever called Colostomy UK's Stoma Helpline, then you will already know that our volunteers have a wealth of stoma knowledge. Every year our volunteers also have opportunities to develop their knowledge further, so that they can better support people like you. Sometimes, our volunteers run training sessions for their colleagues. At a Zoom coffee morning last year, Ken Edwards talked to us all about the Mitrofanoff procedure. Here is a summary of what he had to say:

The Mitrofanoff Procedure and Support

By Ken Edwards

Mitrofanoff Procedure

Professor Paul Mitrofanoff (pronounced MY TROFF AN OFF) created the procedure in 1976. It is also known as the Mitrofanoff Appendicovesicostomy or a Continent Urinary Diversion. It permits bladder drainage where voiding or urethra self-catheterisation is not possible. For the patient it helps them to maintain dignity and means there is no need for an indwelling catheter or stoma bag.

The procedure forms a channel between the bladder and the wall of the abdomen which allows intermittent self-catheterisation. The Mitrofanoff is usually made from the small bowel. One end is tunnelled into the wall of the bladder to create a valve that acts as a continent mechanism, the other is passed through an opening in the abdominal wall to form a small stoma through which a catheter can pass to empty the bladder 4-6 times a day.

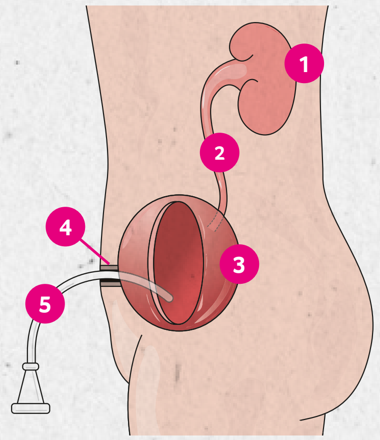
The Mitrofanoff is often situated on the right-hand side of the lower abdomen just below the underwear line, or for cosmetic reasons another possible site is the belly button.

Why have a Mitrofanoff?

Incontinence of urine via the urethra, or being unable to pass urine via the urethra, are key reasons. A Mitrofanoff may be an option in the following conditions: congenital birth malformations (e.g. bladder exstrophy, bladder epispadias, spina bifida, and neurogenetic bladder), multiple sclerosis, spinal cord injuries and paraplegia, bladder cancer, and, in some cases, prostate or bowel cancer.

The procedure is frequently carried out in conjunction with other procedures where satisfactory voiding function may not be possible.

When you leave hospital, you will have the Mitrofanoff and supra pubic catheters in for about six weeks. You will then go back to hospital to have them removed and start learning how to use your Mitrofanoff.



① Kidney ② Urethra ③ Bladder or Neobladder ④ Continent channel which is catheterised to empty urine ⑤ Catheter

Looking after your Mitrofanoff

- » You must catheterise four to six times a day
- » Do at least a weekly wash out
- » Have a daily glass of cranberry juice (this helps to prevent infection)
- » Drink at least two-three litres a day
- » Every three months you may need a B12 injection

Possible post-surgery complications

Stenosis when narrowing of the channel occurs. If the channel becomes narrow, a first step would be to leave a catheter in situ for one week. if narrowing continues you may require a revision and in some cases more significant surgery.

Stenosis can occur more frequently when the stoma is formed through the belly button.

Leaking can occur via the stoma. This can be due to a non-functioning valve, a small bladder, or high-pressure bladder. This can be assessed by a non-invasive test called urodynamics.

Sometimes leaking can be resolved with a course of pills, Botox injections or having a bladder augmentation.

Stones can be produced in the bladder when it is not fully drained. Due to the type of tissue used for a Mitrofanoff, bladder augmentation or neo bladder, there will be a build-up of mucus within the urine, which can create stones.

Infections can develop when there is low fluid input to flush the kidneys and when the bladder is not fully drained. This is why drinking is vital. Urinary tract infections can also occur when the bladder is not fully drained and incomplete emptying of all the bugs the bladder produces. Poor hand and catheter hygiene can also result in infections.

The Benefits

The Mitrofanoff procedure can enable patients to maintain a normal quality of life and dignity.

Mitrofanoff Support

Mitrofanoff Support was set up when Kyla Rogers sought help after 11 years of living with a Mitrofanoff. It became a registered charity in England and Wales in January 2012. It provides people with emotional support, reassurance and information about the Mitrofanoff procedure.

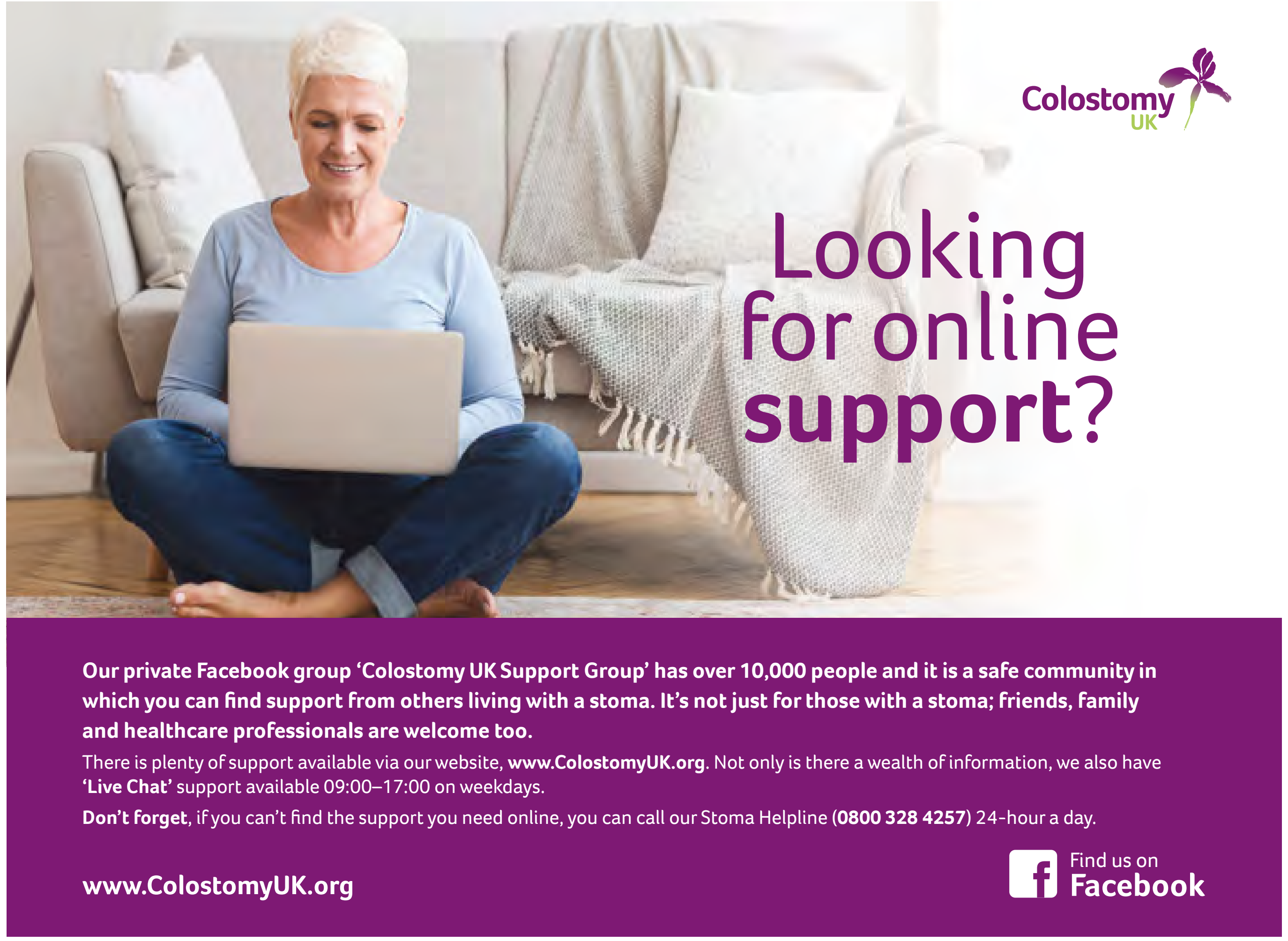
Patient Education Days

The charity holds two Patient Days a year, one in the north and the other in the south, with presentations, workshops, a companies' exhibition, and a chance to meet others.

Mitrofanoff Support has a specialist nurse and two paediatric nurse specialists. The charity is proud of their children's services, which include working to develop children's games and books. It has just launched Generation Z headed up by a young trainee doctor to support 15–24-year-olds.

You can visit their website for more information **mitrofanoffsupport.org.uk** and follow them on Facebook, Twitter and Instagram.

Email **info@mitrofanoffsupport.org.uk**



Colostomy UK

#ActiveOstomates

active ostomates®

Giovanni Cinque
Fundraising & Campaigns Manager
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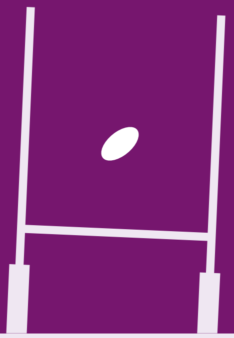


Community Chair Yoga and Creative Minds art classes return

After an absence of two years, we are delighted to announce that our face-to-face Creative Minds and Chair Yoga classes are slowly but surely starting to return.

Our Creative Minds art classes provide something to stimulate both the mind and body, as well as being a fun activity. We provide all the art supplies and aprons so there's nothing to stop people from getting involved. The sessions are delivered by our partners and friends, Creative Minds, and delivered through stoma support groups.

No matter how old or young you are, chair yoga can help strengthen your core, strengthen your muscles, and relax your body and mind. Our Chair Yoga classes are delivered through stoma support groups too. You can also have a go at some hospital stoma care open days.

Later this year, we are hoping to bring back our Swimming events. We are currently looking for organisations who are interested in partnering with us to host one in their area.

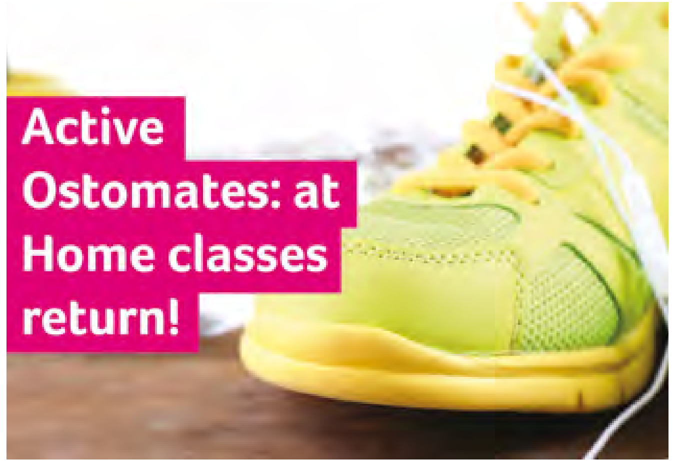
If you are involved in a support group or other community organisation and would like to arrange a Chair Yoga or Creative Minds session(s), or are interested in working with us to deliver a Swimming event, please email: **Giovanni.Cinque@ColostomyUK.org**

New virtual classes

Even though our community sessions are returning, our Active Ostomates: At Home virtual classes have proved so popular that we will be continuing to run these too, for as long as demand continues.

We're excited to announce that for the first time we will be offering an eight-week block of Pilates classes commencing on 9 June. Delivered by cancer and exercise rehabilitation specialist Heather Oakes, just like our yoga classes these will concentrate on strengthening the body with an emphasis on the core.

New Yoga, Chair Yoga, and Mindfulness classes will also be starting again from late May. To sign up for them and our Pilates classes, or to find out more please go to **www.ColostomyUK.org** and visit the Active Ostomates page.



Team Colostomy UK update

In the last issue we looked back on a hugely successful 2021 for our Rugby League team, who are now two games into their 2022 season.

The year kicked off on 3 April when the team travelled to the South Leeds Stadium, home of Hunslet RLFC, to play York Lokos in a curtain raiser to Hunslet's League one match with Oldham.

An entertaining game featured two of Hunslet's Hall of Fame members, Mick Coyle and Steve Pryce. Mike and Steve guested for Team Colostomy UK, which increased the interest in our game amongst Hunslet's supporter base, and thus helped raise the profile of the team and charity in the South Leeds community.

After the game we were able to meet the Lord Mayor of Leeds, Councillor Asghar Khan, who gave his support to our next fixture on 22 May (just before the publication date of this edition of Tidings).

The game is against the British Asian Rugby Association and will take place at the home of Batley Bulldogs, as a curtain raiser to their championship fixture with London Broncos.

The aim of the game is to start to raise awareness of Colostomy UK and the support available from us in some of the harder to reach communities of the country. There will be more details on this game in the next issue as well as the team's 17 July appearance in the London 9s competition.

If you would like to go along and watch the team in the London 9's more information can be found at www.london9s.uk

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's full of lots 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. Also, don't forget to read this edition's Dear Nurse feature (see pp. 16-17).

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**

Colostomy UK

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'd like to thank the following for their support:
Sarah Pannell who ran the Brighton Marathon in April; Suzanne Sapsed who is taking on the virtual South Coast challenge; Anthony Hartley who ran the Retford Half Marathon in March; Steven Whyte, Alistair, and Stephen who walked the West Highland Way in April; Emma and Bobby for their 15-mile sponsored swim; and Paul Turner who ran the Manchester Marathon.

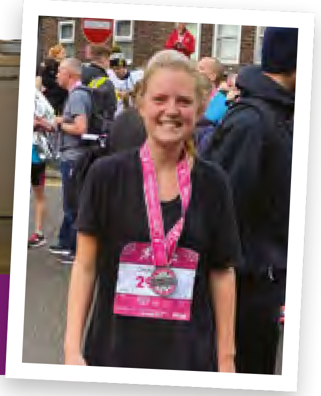
Thank you also to the Yorkshire Building Society Foundation for supporting our volunteers' training.

Get ready for this year's Step Up For Stomas!

Last year we were delighted that so many of you took part in our first Step Up For Stomas challenge. Hundreds of people, on their own or in teams, walked, ran, climbed and even crawled 160,000 steps in September, raising funds to help us better support the 160,000 people in the UK who have a stoma.

We'll be announcing this year's challenge on 1 June and, just like last year, the challenge will start on 1 September. Make sure you keep an eye out on our website and social media for the big announcement on this year's theme.

The next edition of Tidings will also include a special Step Up For Stomas insert.



Joyce's story

Late last year Charlotte Crossland ran the Yorkshire Marathon, raising over £750 for us including Gift Aid. She was inspired to put on her running shoes after seeing how her grandmother Joyce has made the most of her life after stoma surgery, and how she has benefited from Colostomy UK's support, and in particular Tidings magazine.

This is Joyce's story in her own words:

"My name is Joyce. I was born on the 15 February 1937.

In early May 2011 I felt in good health, but whilst showering I thought I could feel a lump in my rectum. I consulted my doctor and after his examination and because I had had polyps removed previously, I was fast tracked to Leeds General Hospital. Eventually in December 2011, I had an operation at St James's Hospital to remove my rectum and I was given a permanent stoma.

The operation saved my life but also changed it completely. The stigma attached to having a colostomy then was cruel. Over the years I've personally experienced this. I've taken it in my stride and pressed on. I've not been beaten. I can openly talk about wearing a pouch and this is nothing to be ashamed of. This medical operation saves people's lives! This was 2011. Now in 2021, this dreadful stigma is going away as the condition becomes more accepted. Colostomy UK and Tidings magazine have helped me enormously and I look forward to it arriving every few months.

Up until 2019 I had no more problems with growths. But when I went for a routine colonoscopy examination a cancerous growth was discovered underneath my stoma. Again, under the guidance of my doctor and team, in February 2020 my lower bowel was removed and on the right-hand side of my abdomen a stoma was formed. So now I have an ileostomy. My stoma on the left-hand side of my abdomen has healed nicely. I've been placed in a cancer follow-up programme. I have check-ups every six months which has given me peace of mind post-surgery.

Over the years I've fallen back into my love for conservation, natural history, and especially the botanical side of nature which I've always had an active interest in. I feel well and go for short holidays not far from home with a friend.

A few months ago, my granddaughter Charlotte (24-years old) said: "Granny Joyce, I'm running the Yorkshire Marathon for you to raise money for Colostomy UK."

This completely took me by surprise, and it touched me. I said this would be marvellous, as my running days are over, but I still have a little puff with my walking stick when I go out. I know I'm a very lucky granny so I have put pen to paper, which I wouldn't have done if Charlotte hadn't inspired me to share my story.

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.


Colostomy UK
Help us support the ostomates of today and tomorrow
Will you consider leaving Colostomy UK a gift in your Will?

If you'd like further details of leaving a gift to us, please call **0118 939 1537** or email: **GetInvolved@ColostomyUK.org**

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.

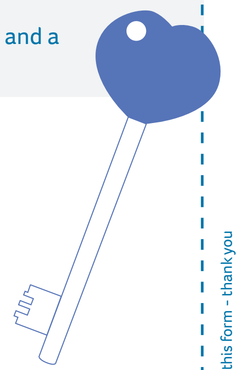
If you live in London and the South, The Midlands, North West, or North East you can book a collection online at **icollectclothes.co.uk/donate/colostomy-uk** or by calling **0344 879 4417**.

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

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

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

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



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

Title:
Name:
Tel:
Email:

Address:
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

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

Title:
Name:
Address:
Postcode:
Tel:
Email:

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Your Letters and Emails

Editor's note:
Thank you to everyone who has been in touch. The mailbag was packed after the last edition. This is great news, but it does mean I have the difficult task of deciding what to print! Stoma Squad attracted lots of positive comment, and hopefully I've managed to capture people's sentiment with the selection that appears below. Please keep those letters and e-mails coming.

Hi,

I am writing in reply to D. McGrath's letter in the spring edition.

I have had an ileostomy for quite a number of years, but only in the last five years had bother with blockages. I did ring Colostomy UK for any advice but unfortunately no one could help. After 5/6 episodes of hospitalisation every six weeks or so with blockages, I was finally sent to a consultant. His advice was don't eat anything with skins on, cook vegetables softer, no seeds, nuts, sweetcorn etc. which doesn't digest.

Thankfully after following this advice no more blockages, but it is harder if you want a treat to eat out as D. McGrath pointed out, as many sandwiches etc. have seeds on, veg are cooked minimally (which I agree is how they should be cooked) but no good for me. It is quite a restricted diet as I also have coeliac disease, but it would be nice to be able to have a sandwich out, without seeds and maybe some softer veg without having to go into detail as to why, which I certainly wouldn't do! Hope this helps anyone who is having similar problems.

Regards, A H

Dear Tidings,

The line-up on the centre pages of Tidings (spring 2022) is wonderful. It makes a charming contrast with the appalling spectacle of women being assessed for the Miss World contest which we saw on the television so recently.

In Tidings we see purposeful brave women celebrating their bodies and not looking for approval from anybody.

Well done Tidings and well done sisters!

Sincerely, Peggy Thomas

……

Dear Editor,

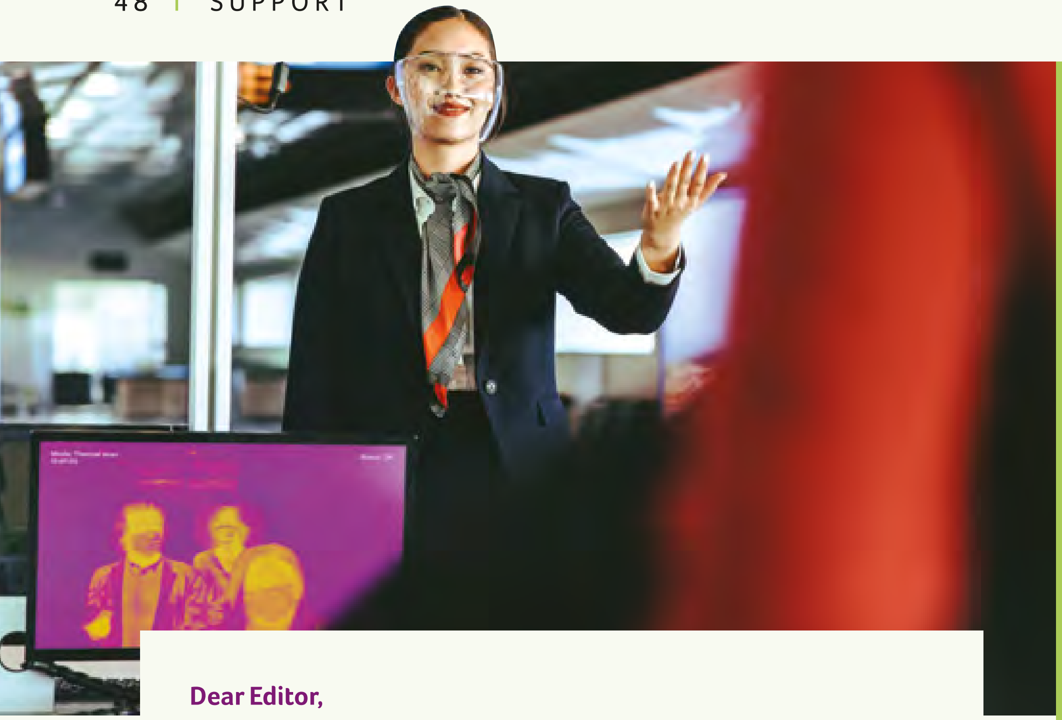
I wanted to send a letter thanking you for the Spring edition. I wanted to especially single out the stunning front cover image and article showcasing the brilliant 'Stoma Squad' with the very inspiring and brave group of women. Wonderful photography and amazing varied stories showing the power of women coming together, the empowerment and building of new friendships through adversity. I found this an extremely positive story for me, thank you.

I also didn't want to forget the equally inspiring 'Team Colostomy' proving yet again the power and bravery of coming together as a team and showing just how active a stoma patient can become. This can be a step too far when you're first recovering and trying to see how far you can go post stoma surgery. Great team spirit and superb positive role models and publicity for all stoma patients.

Both of these amazing groups really helped me feel a little braver to speak about my condition, I'm sure there are many of us who feel uncomfortable and nervous at times. I've also been able to get back to playing badminton - it really helps you to feel normal when you can go back to the things you loved to do before your stoma journey began.

Massive shout out to all the people you've showcased over the years who have shared their stories both the highs and lows and how they've still held positive views to help them move on in life.

Keep up the great work, Karen Clegg



Dear Editor,

I read with interest the article on airport travel (spring 2022).

I have a stoma and each time I go through the x-ray machines I have been taken to one side as my stoma obviously shows up on the machine. I discreetly mention to the security staff that I have a stoma and only on one occasion (at Leeds/Bradford airport) have they shown any awareness and discreetly tapped me down and allowed me to carry on. On all other occasions (Heathrow/Gatwick/Manchester) I have been asked, with little compassion to go to a private room for a strip-type search.

As I usually travel alone this means that my hand baggage, which has successfully made its way through the x-ray machine, just sits waiting for my return. This can be 20 minutes depending on where the room is you are being taken to and finding the appropriate staff to carry out the search. I find this most traumatic, as in the bag is my money, tickets, phone, tablet, camera, jewellery and stoma supplies - in fact the most important things.

Even though my bag has successfully gone through the machine I am not allowed to take this with me, but surely for peace of mind I should be allowed to do this.

On one occasion I asked for my bag to be put somewhere safe, but was told it was fine where it was as CCTV was in operation. I have a friend whose passport was stolen during such a time! They once agreed to put the bag behind the security barrier and then 20 minutes later when I returned from the search room the staff had changed and even though it was fine, they took everything out of my bag, checked and tested every piece of my make-up, bag lining, purse etc. So not only did I have to go through the indignity of a strip search but was made to feel like a criminal in front of the other travellers. Although I gave myself plenty of time to go through security, this whole process worried me as time was ticking.

I just thought my experiences would be useful during your next meetings with airports across the UK.

Regards, Dorothy Ternent

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.

Dear Editor,

Following your features about swimming (spring 2022) and having to change the bag because it is wet, I place one of my complementary dry wipes between my bag and my underwear.

This absorbs the moisture without passing it through to my clothes. After a fifteen-minute walk home, everything is dry and I can remove the wipe and do not need to waste an empty bag!

Yours, S White

Colostomy UK

Every 39 minutes someone in the UK has stoma surgery.

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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.**

The Outlook Staffordshire Ostomy Support Group

At our meeting in May our speaker was Rebecca Loughhead from Middleport Pottery.

Our next meeting is on **Tuesday 19 July at 7.30pm** when our speaker will tell us about the help she receives from her assistance dog and their charity.

Further meetings are on **Tuesday 13 September at 7.30pm** and **Saturday 19 November at 2.30pm**.

The ANNUAL PATIENT DAY AND EXHIBITION will be on **Saturday 15th October 1pm – 4pm.**

All meetings will take place at Bradwell Lodge Community Centre, Bradwell Lane, Porthill, Newcastle, Staffs ST5 8PS.

For further information, contact: Moira Hammond: 07788 402195

Colostomy UK private Facebook Support Group

In difficult times, we all need support. The Colostomy UK private Facebook Support Group provides solidarity, compassion and friendship in equal measure for those who join.

Membership is open to ostomates, their families and their friends. It is a safe place where you can interact with people who understand what it is like to live with a stoma.

If you are on Facebook and haven't joined yet, why not take a look at this friendly digital community? We actively monitor and moderate the group to ensure a positive environment for all. Joining is a simple process, you just need to go to our Facebook page, click on the group and apply to join.

Picture perfect

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

Her artwork of male and female forms with either a colostomy or ileostomy are now available for sale via our online shop, and Emily is kindly donating all the proceeds to Colostomy UK.

You can order online at:
www.ColostomyUK.bigcartel.com

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

Channel Islands

Guernsey

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

Jersey

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

England

Berkshire

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

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

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

Bristol

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

Buckinghamshire

High Wycombe Stoma Support Group
T: 0800 318965

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

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

Cambridgeshire

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

Cambridgeshire Ostomy Group Support
E: cogs-stoma@hotmail.com

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

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

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

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

Devon

Devon IA
E: devon@iasupport.org

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

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

Dorset

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

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

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

Essex

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

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

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

Optimistic Ostomates
Angela Taylor T: 01702 385 510

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

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

Hampshire

Replummed Stoma Support Group
W: 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 Man

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

Isle of Wight

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

Kent

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

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

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

GOGS (Gravesend Ostomy Support Group)
Tracey T: 07779 155 846
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
Angela Davy
T: 020 8510 5318 or 020 8510 7599

Newham Stoma Support Group
Contact Lauren King T: 020 7055 5576

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

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

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

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

Merseyside

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

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

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

Middlesex

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

Norfolk

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

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

Northamptonshire

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

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull T: 07714 479 320

Hexham Ostomy Group
Marie Douglas 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
E: nuneatonstoma@aol.com
T: Bob: 07564 680 803

West Midlands

Coventry Stoma Support
Martin T: 07947 385 643

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

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: www.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

Northern Ireland

County Antrim

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

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

County Armagh

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

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

County Down

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

Ulster Hospital
Hazel/Martina T: 028 9055 0498

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

Londonderry

Causeway Support Group
Mary Kane T: 028 7034 6264

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

Wales

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 / 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
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