Spring 2020 | Issue 57

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Tidings

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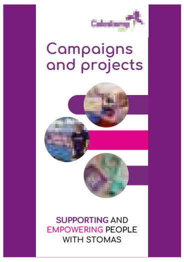
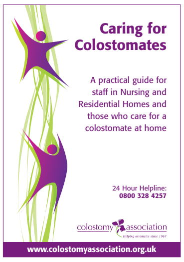
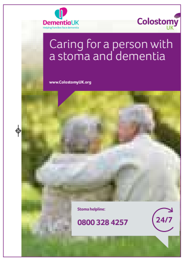
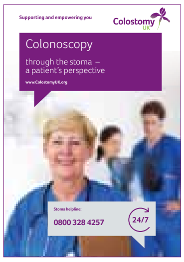
Active Ostomates Sport and Fitness after stoma surgery


Campaigns & Projects Flyer


Caring for Colostomates

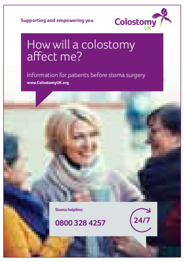

Caring for a person with a stoma and dementia

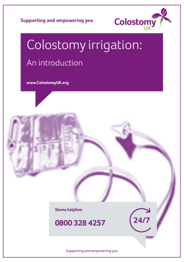

Colonoscopy through the stoma

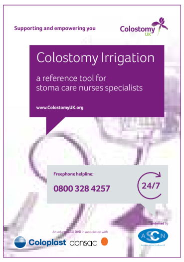

Fundraising Pack

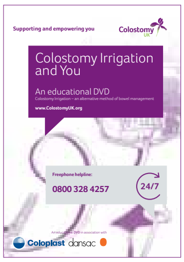

Healthy Eating

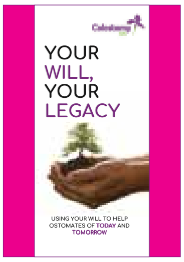

Helpline Cards


How will a Colostomy affect me?

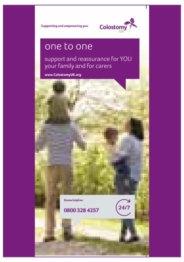

Irrigation Booklet


Irrigation DVD (nurses)


Irrigation DVD (patients)

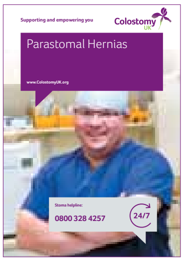

Legacy Flyer


Living with a stoma

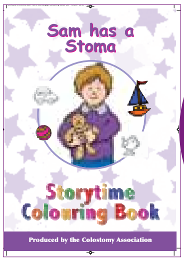

One to One (join us) Flyer


Ovarian Cancer and stomas

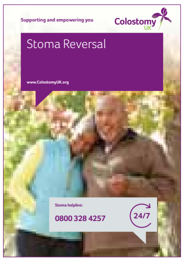

Pain & Discomfort


Parastomal Hernias

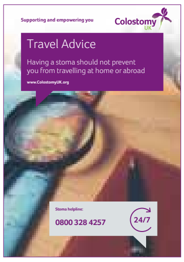

Rectal Discharge


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

Dear readers

Colostomy UK

Editorial Team

Editor, Writer & Researcher
Richard Biddle

General Manager
Libby Herbert

Colostomate & Volunteer
Jackie Dudley

Colostomate & Volunteer
Rosemary Brierley

Data Analyst & Publishing
Arvind Anand

It is Friday 31 January and as I write this the clock is ticking down the hours to 11 pm and Brexit (finally). I for one am glad it's over. I say this not with any intention of making a political point about the rights and wrongs of leaving the European Union, but simply because after three years of incessant press coverage I'm sick to death of hearing about it. I fear though that rather than being the end, all the 31 January will mark is the start of a new chapter of intense media speculation! As my father said to me: "It's worse than the Profumo affair, the press didn't shut up about that either".

But as the media gears itself up for another feeding frenzy, life goes on in the real world. And if ever you wanted an insight into what that life might look like, then look no further than this edition of *Tidings.* Our cover story looks at a subject that rarely gets much attention: the challenges faced by parents who have a child with a stoma. You can see the young ostomate from this story on the front cover! We have two other Real Lives' stories. Lynn Farmer talks about how she coped with being told she was too high risk for stoma surgery. We also catch–up with Garry Howe whose story first appeared in *Tidings* a couple of years back and learn about his recent exploits motorcycling around Spain.

I'm sure that people will be pleased to hear that we have 'Dear nurse' back again, with Tina Maddams answering questions on the issue of rectal discharge. Staying with healthcare professionals, Lisa Hall, who is a community stoma nurse working in the Bradford area, has written a really interesting article about the religious and cultural needs of patients she sees. This is a very informative piece and timely too, given that Ramadan starts on 23 April. We have **Colostomy UK's** volunteers who irrigate and irrigators from our private Facebook group to thank for this edition's irrigation article. Together they have contributed a whole range of top tips. There is something for experienced irrigators and those who have just started (or are thinking about) this method of stoma management.

As usual there is a **Colostomy UK** news update and Giovanni gives us the lowdown on fundraising and our Active Ostomates project. We also have a new feature from the **Colostomy UK** team. Emma Howell our Volunteers Manager talks about why volunteers are so important to us and shares some of the things our volunteers get up to and say! To round things off we have two further articles. Jane Green, who is an area co–ordinator for Ehlers–Danlos Support UK, explains why some people with the syndrome go on to require stoma surgery. Bob Bailey from the Romanian Ostomy Patients Support Foundation (ROPSF), who **Colostomy UK** have worked with for many years, gives an update on the foundation's work, including some recent nurse training delivered in the country. As you will see, although stoma care in Romania has changed for the better since ROPSF's first involvement in the country back in the 1990s, it still has a long way to go.

Best wishes and happy reading!

Richard

Richard Biddle
Editor,
Writer & Researcher

trio ostomy care™

REBECCA'S STORY

After being **diagnosed with ulcerative colitis** at 19, I experienced symptoms for the next ten years with medication never seeming to work. Then at the age of 30 I was **diagnosed with bowel cancer and stoma surgery was the only option**. When I returned to hospital for my first chemotherapy session, I suffered a drug-induced seizure, then 24 hours later I suffered a second seizure followed by a series of four cardiac arrests. I was rushed to the Intensive Care Unit by the duty crash team, where my family were prepared for the worst.

After several weeks in hospital and a long recovery at home, I was desperate to get back into sport. Before my surgery I loved running and was able to run 10km, usually without too many problems with my colitis. In the months after returning home I could barely walk a couple of hundred metres, through weakness and pain. Each day I walked a bit more, albeit, to the next house in the road and back.

Sport is what has kept me 'sane' after everything I went through and I continue to use it to give me a purpose, while I haven't been well enough to work. In September 2017 I walked my first kilometre and in November I jogged the same distance for the first time. I built up the distance I could run and by Christmas 2017, I could run 6km. Much to mine and my doctors' amazement, in September 2018 I ran my first ever Half Marathon, raising over £1000 for the Royal Surrey County Hospital Charity, with the funds going to the Intensive Care Unit.

I found running so much easier with a stoma than with colitis but not without its problems.
I wear Vanilla Blush support wear to prevent hernias, I use **Trio Elisse Skin Barrier** to help my bag stick to my skin rather than slipping off when sweating, and I will not run without **Trio Silex Flange Extenders** to stop the edge of my bag cutting. I also love **Trio Elite Remover Spray** and would be lost without these products

Order your **FREE** samples at www.TrioOstomyCare.com

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Contents

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

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

How to contact us

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

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

To request (or cancel) your quarterly copy of *Tidings*
0118 939 1537

info@ColostomyUK.org

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Letters, articles or other submissions

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Reading, Berkshire, RG1 4QA

info@ColostomyUK.org

Advertising enquiries
For a media pack and advertising rates: **0118 918 0500**

Arvind.Anand@ColostomyUK.org

Social media:

Find us on Facebook

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!

Colostomy UK news

Real lives

Wellbeing

Fundraising

Support

Donating to Colostomy UK

An annual donation of £20 (or whatever you can afford) allows us to produce *Tidings* and to continue our vital work, supporting, and empowering ostomates – see page 40 for 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
E: libby.herbert@ColostomyUK.org

Although you won't be reading this until March, I'm still going to start by saying a happy New Year to all our readers. Before bringing you up–to–date with what we've been doing in the first months of 2020, I thought you like to see some pictures from the team Christmas dinner. Sadly not everyone was able to come along, but we all had a great time nonetheless!

British Health Trade Association (BHTA) Scotland conference

We were pleased to attend the above in January. The theme for this year's conference was twenty years of devolution and what it has meant for Scotland. Amongst the speakers was stoma care nurse Angie Perrin who gave an interesting talk explaining the importance of the Association of Stoma Care Nurses (often referred to as ASCN) and the role that stoma care nurses have in supporting patients both pre and post–surgery.

Scottish Stoma Forum

Luckily the BHTA conference coincided nicely with the Scottish Stoma Forum in Glasgow. This saw representatives from all three of the main stoma charities, healthcare professionals and the stoma care industry come together to discuss the latest challenges and trends in stoma care in Scotland.

A January visit to Westminster

Thanks to an invite from Martyn Cheney of Bramley Buffaloes, Giovanni, our Fundraising and Development Manager, along with myself and our president Ian Daniels FRCS, attended the All Parliamentary Rugby League Group annual dinner. This great networking event gave us the chance to raise awareness about stomas and what it is like to live with one, with MPs, as well as people from the worlds of rugby league and the media.

Respond and Pelican Health awareness campaign

L–R Guest speakers: David, Amber, Allan, Angelina, Keith, Jake and Rachel

We were thrilled to be invited by Respond and Pelican Health to the 'kick–off' meeting, in which they called for Cardiff to lead the way in raising awareness through their campaign 'Support the need for greater understanding for people living with a stoma and invisible illnesses'. It's great to see others driving change too. There was a fab panel of guest speakers too, raising awareness of every day issues faced by ostomates. **#BeTheChange**

Libby Herbert
General Manager

We are hiring:

Marketing and Communications Manager – Full time – based in Reading, Berkshire

Do you have the vision to develop the marketing and communications strategy for our growing national charity and the drive to manage and deliver it, ensuring buy–in along the way from all stakeholders?

This is a senior position, suitable only for high–calibre, hard–working people, who are educated to degree level or equivalent and have a minimum of three years marketing and communications experience. The marketing and communications manager is responsible for the charity's website and social media platforms. Hence high–level computer skills and design skills are a requirement of the role, along with an in–depth technical knowledge of popular social media platforms.

On a day–to–day basis you will be creating written content for a variety of audiences and suitable for a range of different media. As such, you must possess exceptional written skills, effective proof reading and a keen eye for a misplaced comma. A gift for spotting and telling stories in compelling and informative ways will be advantageous.

For a full job pack, please e–mail the recruiting manager Libby Herbert: **libby.herbert@ColostomyUK.org** with a covering letter.

We also want to recruit two trustees (these are unpaid positions)

1. **Fundraising trustee:** The overall role of a Fundraising trustee is to provide strategic oversight of **Colostomy UK's** fundraising and communications campaigns, making sure these are carried out in legal, honest and accountable ways. Act as a mentor to our Fundraising and Development Manager & Marketing & Communications Manager to drive our charities fundraising activities at strategic level.
2. **HR trustee:** To provide strategic oversight of **Colostomy UK's** human resources, working with the Trustee Board and General Manager to develop policies and practices in line with the charity's objectives. The post holder will be responsible for assessing the risk and measuring the impact of HR interventions, ensuring the charity meets its legal obligations while at the same time taking account of the impact on our beneficiaries, volunteers and employees. The post holder will be expected to provide HR advice and guidance and will ensure **Colostomy UK** adheres to current best practice.

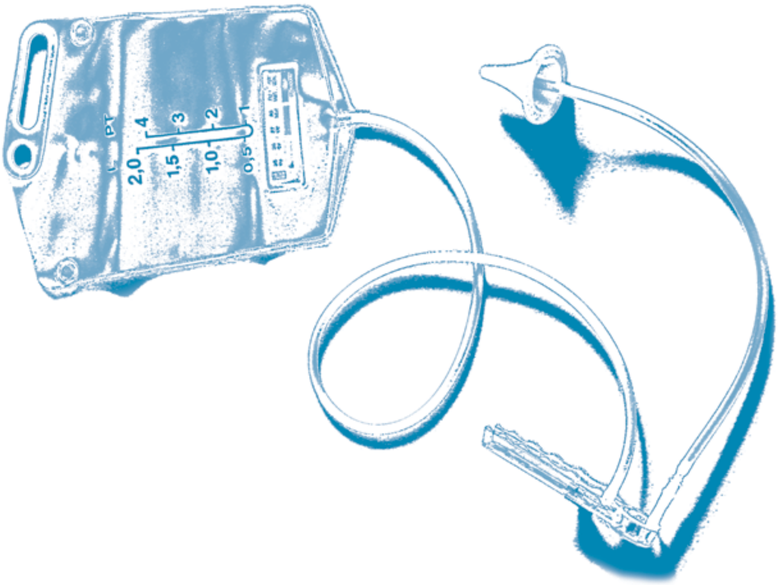
E–mail:
libby.herbert@ColsotomyUK.org if you are interested.


SOS
LBF

Irrigation and you

Do you irrigate? If not, are you interested in trying? If you would like to try irrigation you should first contact your stoma nurse to see if you are a suitable candidate. If you get the go ahead they will arrange a time to teach you. For more information see the Colostomy UK website or order our *Colostomy Irrigation and You* DVD using the form on page 21.

If you have any questions, comments or experiences of irrigation you'd like to share please write to me at **Colostomy UK** or send an e–mail to: **Richard.Biddle@ColostomyUK.org**



In the last edition of *Tidings,* stoma care nurse specialist Ambra Berinara, took us 'back to basics', explaining what irrigation is, who can and can't irrigate, and the pros and cons of managing your stoma in this way. The article was very well received and prompted a number of our readers to get in touch, with a range of queries and general 'irrigation' enquiries. Thankfully, with many of our volunteers being irrigators, we have a wealth of experience to draw on!

Because of this, I thought it would be a good idea to follow up Ambra's piece with a selection of top 'irrigating' tips from our volunteers. I also asked for help from members of our private Facebook group who irrigate. The response was great…so great in fact that I haven't been able to list them all. As you will see, there's a broad range here, from words of advice for absolute beginners, through to tips and things to bear in mind when irrigating on holiday and in foreign countries.

General tips

- When you first start irrigating, perseverance is the name of the game – but it's worth the effort!
- During training my stoma care nurse said that if I preferred the 48–hour method, then to set up my routine for this from day one, irrigate every other day and not be tempted to irrigate in between because of breakthrough. I followed her advice. It took about three months of varying degrees of success until I could say it worked.
- It's very important to relax while irrigating: good posture, no slouching, but inwardly relaxed. If you are too tense you may struggle to let the water in.
- Take your time. Don't rush the process and allow some resting time afterwards for any residual output.
- Develop a routine – morning or evening, whichever best suits your lifestyle. Have things on hand to keep yourself occupied (iPad, book, phone, radio etc).
- It's important not to get dehydrated when you irrigate, so I always drink a 500ml bottle of water while I am irrigating. I then fill the empty bottle with tap water and use it to rinse the sleeve. I find this much easier than using a jug.
- My top tip is to drink, drink, drink!! Dehydration is the enemy of irrigation.
- Use nice comfortably warm water, too cold won't work and too hot may cause damage.
- I put K-Gel on the end of the cone before inserting.
- Stretching your arms up towards the ceiling when you think your output is finished – you may encourage the last output.
- Place left hand on right side of abdomen, then place right hand on top of left hand and firmly stroke across the abdomen from right to left a few times. Do this during the irrigation process.
- When the sleeve is rinsed, dry the outside and roll it up. Secure with pegs top and bottom. I then put on my bath robe and maybe make the bed, put some washing in the machine, hang washing out. If there is any more output it will be released.
- One thing I do when irrigating is take my portable television into the bathroom which allows me to catch up with what I have missed as well as pass the time.

CONTINUED ON PAGE 10, COLUMN 1

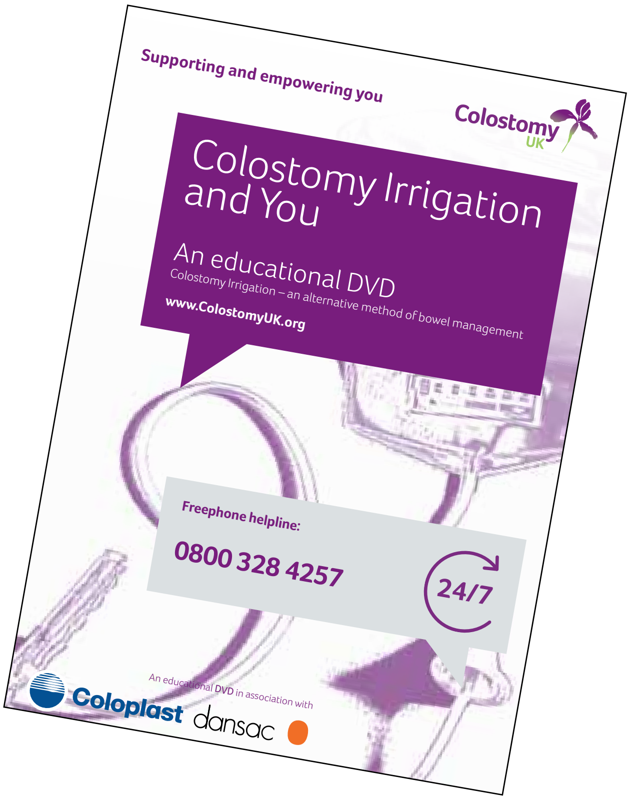
CONTINUED FROM PAGE 9 COLUMN 2

- I use a little fold–up table from Amazon to put out all of my irrigation gear in front of me. It folds up flat and goes in the broom cupboard afterwards!
- Don't rely solely on irrigating to manage output, look at diet and eating patterns to complement your irrigating routine.

Tips when travelling in the UK and abroad

- We had lots of suggestions for things to use to hang up the water chamber while staying away from home. These included:
  - A piece of wire coat hanger.
  - Two trouser hanger clips together work a treat!
  - A hook to go over the shower door, the bathroom door or curtain rail.
  - An 'S' shaped hook.
  - A tea towel hook for a kitchen door.
- Take more supplies than needed, three weeks for two weeks. Take a drainable bag and Loperamide (Imodium) tablets.
- If abroad, do not have ice in your drinks and always use bottled water for irrigating.
- I always use bottled water for irrigating when I am abroad. You can warm this to the right temperature, by putting the bottled water (still in its bottle) in a sink filled with warm water.
- Take all your supplies in hand luggage, splitting them with a partner if necessary.
- I always take two complete kits when travelling: one in my hand luggage and one in the hold luggage.

Thank you to everyone that sent me their tips. I hope people have found some of them useful.



Supporting and empowering you

Colostomy UK

Colostomy Irrigation and You

An educational DVD

Colostomy Irrigation – an alternative method of bowel management

www.ColostomyUK.org

Freephone helpline:

0800 328 4257

24/7

An educational DVD in association with

Coloplast dansac

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Easy Fundraising

easyfundraising
feel good shopping

Easy fundraising is a website that allows you to donate to **Colostomy UK** at no extra cost to you while you shop with hundreds of the UK's top High–street brands.

All you need to do is:

- Register as a supporter on the Easy Fundraising website and
- Make sure that **Colostomy UK** (Colostomy Association) is added as your supported cause.
- You can then accumulate donations while you shop with any of their partner retailers.

For more information or to register just visit:

easyfundraising.org.uk/causes/colostomyassociation

feel good shopping

Small changes, big impact

Pelican & Respond Healthcare are behind a movement to improve the lives of people living with stomas. Campaigner Amber Davies explains why

Those who live with a chronic illness know all too well that it isn't just the physical symptoms that can present challenges. Very often, a lack of public understanding can mean that everyday life suddenly becomes laden with unnecessary obstacles.

This is especially true for people living with a stoma – an opening in the abdomen that allows waste to be collected outside the body in a bag. However, with the help of UK-based health companies Pelican Healthcare and Respond Healthcare, a new action group has been formed by those affected by the condition to lobby for changes that could have a significant impact on their day-to-day lives.

Even changes as seemingly minor as altering toilet signage could bring untold benefits, explains group member Amber Davies (right). "I've experienced negativity because of my condition. When using accessible toilets, people have been verbally abusive because they think they aren't for me, and I've even been questioned by security guards."

The group is currently working with the Welsh Government to replace the current wheelchair symbol to reflect the fact that not all health issues are immediately visible.

Waste collection is another issue. "Because of my stoma, I use up the space in my bin very quickly, which can often leave me facing a fine from the council," Davies explains. The group is calling for the widespread adoption of specialist collections that only a handful of areas already offer. "There has to be a greater recognition of the needs of people living with a stoma." Mat Stratton, MD of Pelican and Respond agrees: "We need more education and a higher level of awareness. People are experiencing issues every day that can be tackled positively, so we'll be working with charities and associates to form one unified voice in calling for change."

#BeTheChange
pelicanhealthcare.co.uk
respond.co.uk

...tea at The Ritz

Lynn Farmer

Over the years I've learned that while each person's stoma journey is unique, they nonetheless share some common elements. One of these is the sense of shock, followed by fear and foreboding that accompanies being told stoma surgery is necessary. Apart from those whose surgery was done in an emergency, I have yet to meet an ostomate who can't remember that conversation with their consultant, that journey home afterwards, those dark days that followed. Many speak of mixed emotions. On the one hand there is hope that the surgery will alleviate or end years of suffering. On the other is dread of the surgery itself, doubts about whether it will be survived and, if so, what life will be like afterwards. Imagine then, riding this roller coaster and doing your best to mentally prepare, only to be told some weeks later that, on reflection, the surgeon feels you are too high risk to operate on. This is what happened to Lynn Farmer and this is her story.

Lynn was born with Poland Syndrome, which wasn't diagnosed until she was 22. This is a birth defect outwardly characterised by under–development of chest muscle and short webbed fingers on one side of the body. The syndrome is very rare and the causes are not fully understood. Current thinking is that the blood supply is interrupted before birth. Beyond its more obvious physical manifestations, people with the syndrome can suffer from other problems including abnormalities to the gastrointestinal tract. Lynn, who celebrates her 50th birthday this year, started to suffer problems with her bowels in her mid–30s. She was variously told that she had irritable bowel syndrome, diverticular disease and a slow transit bowel. No overt connection was ever made with Poland Syndrome. Her treatment, which included antispasmodic tablets and various changes to diet, proved ineffective and over time her symptoms got worse.

By 2017 Lynn had reached crisis point and was living with the embarrassment of faecal incontinence. Indeed it had got so bad, that in the end she was wearing bulky incontinence pads, incontinence pants and then ordinary pants on top, just to make sure she didn't leak onto her clothes. With treatment options exhausted, Lynn was eventually referred to a colorectal surgeon. She suggested trying a sacral nerve stimulator, but warned Lynn that if this didn't work, then a colostomy was the only option. Lynn left the consultation in shock, but also optimistic that the stimulator would work. When it didn't and her symptoms continued to worsen, Lynn started to research colostomies and began the process of coming to terms mentally with what the future might hold.

When Lynn saw her consultant next they discussed the surgery at length and, because of Lynn's complex health issues, it was arranged that she would also see the anaesthetist to discuss the risks from this perspective. Lynn says that this latter meeting was a lengthy one, but the outcome was encouraging. The anaesthetist explained that while Lynn was high risk, things could be put in place to allow the surgery to go ahead. Although Lynn was obviously concerned, her outlook was positive. She was now seeing the surgery in terms of it being the light at the end of a very long tunnel. But, the letter that arrived in the post, thrust Lynn back into the darkness. Rather than being a date for her op, it turned out to be from her consultant, saying that on reflection she considered Lynn to be too much of a risk to proceed. In her view the most likely outcome would be Lynn in intensive care on a ventilator, with her family having to decide when to switch off the machine.

When I spoke to Lynn, it was clear, even now, just what a devastating blow this news was. But, as Lynn said, there was little she could do. She thought it would be selfish to put her family in such an appalling position. Likewise, she felt that she must bow to the judgement and expert knowledge of her medical team. Once Lynn had got over the initial shock, she vowed to get on with her life and make whatever adjustments were necessary. However, in the next 12 months her symptoms got even worse. She remained incontinent and started to suffer what she describes as 'bowel explosions'. It wasn't long before Lynn was housebound as she was so frightened of getting in a mess. Even at home it was difficult, with the number of accidents she was having. Beyond

the physical, the mental toll this took on Lynn was considerable. Alone at home, with plenty of time to reflect on her situation, Lynn described to me being an "utter mess". But it was also during this period that Lynn decided to try and act. Aware that she couldn't continue to live as she was, she came to the conclusion that, regardless of the risks, the issue of stoma surgery needed to be re–visited. She thus wrote (what turned out to be a number of letters) pleading with her consultant and anaesthetist to reconsider. Lynn didn't stop there either. Having set surgery as her goal triggered a fight back of another kind. Lynn decided to get fit for surgery. Despite her ongoing problems, she found the courage to go out again and joined a gym, with the idea of losing weight, getting fitter and reducing the 'surgical risk'. Quite where Lynn found the strength to do this remains a mystery, even to her. Perhaps it was that innate survival instinct we seem to possess, 'kicking in' and unleashing some inner strength. What Lynn is sure about though, is that regaining some control of her destiny, helped her to heal mentally. This improvement was boosted greatly when her medical team agreed to proceed with surgery. To quote Lynn directly: "To say I was happy was an understatement, which I know might sound strange that I was happy about going into surgery, but this was my last chance of some sort of a normal life".

With a High Dependency Unit (HDU) bed booked and ready, Lynn went down for a loop colostomy on 7 August 2019. Lynn says she went into theatre with a positive attitude telling her medical team (and herself) that she would be fine. Of course she was nervous, but given what had gone before and the circumstances in which she had been 'existing' it seemed to her that the light at the end of the tunnel had been rekindled. She looked forward to the promise of a new chapter in her life and being able to arrange her 50th birthday celebration in 2020. Lynn's surgery went well. In fact, it took less than two hours and the HDU bed wasn't needed. By day six she was able to change her bag, was gaining confidence and looking forward to being discharged. Sadly, this was slightly delayed because Lynn got hospital acquired pneumonia (a known risk as she is a severe asthmatic) and had an Addisonian crisis (a rare and potentially fatal condition where the adrenal glands stop working properly), but both eventualities had been prepared for. And, after the speedy intervention of IV antibiotics and hydrocortisone, Lynn recovered and was discharged on day eight.

Although the expression 'and she never looked back' is over–used, it is one that aptly applies in Lynn's case. When we chatted at the end of January she was doing remarkably well for someone just five months post–op. Like all new ostomates she has had her fair share of hiccups, but her quality of life is incomparable with just eight months ago. She is no longer housebound and has recently started swimming and aqua aerobics, something that she used to love as a younger woman and thought she had lost forever. But Lynn is also realistic. She admits that she has days when she feels low, both physically and mentally. Her coping mechanism for these is to remember how things were and how they are now. In July last year she struggled to leave the house and her future was unclear, now she is looking forward to enjoying a birthday tea at The Ritz with her two sisters, one of whom is coming over from Australia for the occasion.

Lynn wanted to tell her story, because reading some of the recent stories in *Tidings* she recognised her struggles in the struggles of others. She drew strength from these. It is her hope that people will benefit similarly from reading hers, even if it is nothing more than to realise that they aren't alone. ■

Written by
Richard Biddle

Halfx3 14v00r00 Photo ID Application | Date of Publication: November 2019 | Copyright ©2018–2019 Colostomy UK | Registered charity no. 1113471

Photo ID Card

The **Colostomy UK** photo ID card can be useful if challenged when using accessible toilet facilities.

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

- **A copy of your prescription or delivery note as proof of eligibility**
- **Passport photo x 1**
- **Payment – cheque or credit card***

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

Alternatively, the form can be downloaded from our website: **www.ColostomyUK.org**

Allow maximum of 10–14 days for delivery.

IDENTIFICATION CARD

Disability Rights UK

The cardholder has a medical condition and needs urgent access to disabled facilities

If found, please return to:

ID card Number

123e45

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

To obtain a **key or a photo identity card** please **complete the form and declaration.** Make your **cheque payable** to **Colostomy UK.** Return all required items to:
Colostomy UK, Enterprise House, 95 London Street,
Reading, Berkshire, RG1 4QA

(If you have any queries or would like to pay by credit card, please contact **Colostomy UK** office:
Telephone: **0118 939 1537** or Email: **info@ColostomyUK.org)**

National Key Scheme – Key and photo ID card purchase

Title:

Name:

Address:

Postcode:

Tel:

Email:

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.

Please **tick** as appropriate:

☐ I would like to receive a **key £3.50** (including postage and packing).

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

NOTE: Please send a copy of your prescription/recent delivery note as proof of eligibility and make the cheque 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.

Signature of self or carer:

Date: / /2020

T57

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

Above the Clouds

Garry Howe

Potes

In the Spring 2018 issue of *Tidings*, Garry Howe told his story about how after emergency surgery and stoma formation due to diverticulitis, he returned to work as a garage mechanic. But the experience had left him with the feeling that he would like to change careers and do something which would benefit other people. In 2015 he began work for the NHS as an ambulance care assistant with Staffordshire Ambulance Service, and two years later became a blue–light driver. He works twelve–hour shifts transferring critically–ill, intensive–care and high–dependency patients between hospitals.

Garry believes it is so important to be open and able to talk about stomas; nurses at his local hospital often ask him to speak to new patients. This led him to become a volunteer for **Colostomy UK.** It was last October when we manned a stand together at an Open Day in Derby that Garry told me about his Spanish motorcycle trip.

When I asked him if he'd always rode a motorbike he said: “I'd never rode a bike before, it was only because a few of my colleagues I work with have got bikes and always spoke about how good it was when you are out on them. With a gentle push, I decided to go for it. If nothing else to prove to myself I can do it.”

In October 2018 Garry gained his full motorcycle license and a month later bought a 2000 ‘W’ plate Suzuki SV650. A paramedic he had worked alongside heard that Garry had taken his advice and now had a bike. So, he got in touch to ask if he would like to join him and two other bikers for a ten–day holiday riding through the mountains of northern Spain.

At first Garry said: “No Way”. He was a new rider and the other three riders had bikes larger, newer and more powerful than his: two had a Yamaha Tracer 900 the other a BMW 1000 XR, all of them no more than two years old.

Not only that, but how would he cope with his colostomy?

Although he has always been quite open about his surgery so all his friends and work colleagues know he has a stoma, Garry still had some concerns. Would he be able to get enough stoma supplies in the panniers on his bike? What if he didn't take enough and ran out! To get there they'd take a 24hr overnight crossing from Plymouth to Santander. How would he manage his stoma sharing a cabin with three others? When they got there, they'd be riding, bodies bent forward over their bikes, for most of the day. How would his stoma cope with that? Would this cause a leak and what would the facilities be like up in the mountains? Would there be anywhere to change his bag?

His wife, Cherry, took the decision out of his hands. She said he must go, and rang the paramedic colleague who had invited him and said that her husband would definitely be joining them. She even told Garry that she would find the €900 he'd need for the trip.

And so, the four motorcyclists set off, riding from Derbyshire to Plymouth in torrential rain. Splashed by huge puddles, cold and very wet, Garry wondered if this really had been a good idea. They boarded the ferry at 4:30pm, dried off and things seemed to be going a lot better. They had something to eat, a few drinks, then they hit rough weather. Seasickness! Garry's stoma, however, caused no problems at all! They docked at Santander at around 3:00pm the following afternoon.

For the first five days, they rented an apartment in Potes, a small town in the Valley of Liébana, as a base from which to explore the surrounding mountains of Picos de Europa. Then they rode on through the Castilla y León and stayed in hotels in the cities of Ponferrada and Burgos.

Changing his bag was never a problem: Garry described the facilities in tiny mountain cafés and filling stations as “very clean and hygienic, better than some toilets I have come across in the UK!” He said: “Leaning over as we rode for stretches of an hour and a half at a time didn't cause any problems with my stoma and wasn't uncomfortable. In fact, it was my shoulders that hurt at the end of the day.”

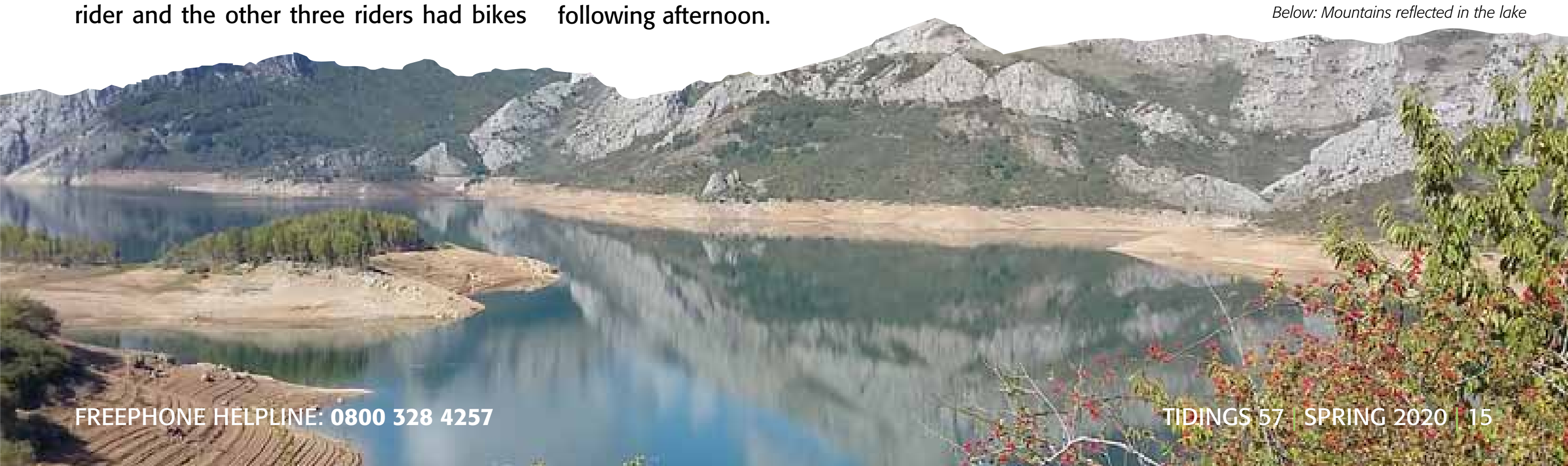
They covered up to 257Km a day. “The scenery was fantastic,” said Garry as he took out his phone and showed me photographs of high peaks reflected in still lakes, white clouds hovering between the mountains below them. They almost had the roads to themselves, and on one occasion travelled for 80Km and only saw one car.

When I spoke to Garry at the Open day in Derby, he had arrived back from his trip just two days earlier, with most of the extra stoma supplies he had taken, just in case, still in his panniers. I asked if he would go again and if he would have so many concerns next time. He said: “Expect the worst. Hope for the best.” And how did he feel now? “So glad my wife made me go.” ■

Written by
Rosemary Brierley

Above: Garry, on the right!

Below: Mountains reflected in the lake



Colostomy UK: volunteers

Emma Howell
Volunteers Manager
E: Emma.Howell@ColostomyUK.org

Welcome to our new, regular feature, devoted to Colostomy UK's volunteers and volunteering with Colostomy UK. In this edition I thought I'd use the opportunity to tell you a little about our volunteer roles and share with you some of the reasons why people volunteer with us.

What is volunteering?

No doubt you will be familiar with the term 'volunteering'. I'm sure many of you will know a volunteer of some kind or another. In fact, some of you might have been a volunteer yourself before, or perhaps are one now, if not for **Colostomy UK** then with someone else.

Charities define volunteering in many ways, but in essence see volunteers as people who do something for them (usually to support people) willingly and without being forced or paid to do it.

Colostomy UK is a volunteer–centred charity. Volunteers and the support they provide have been integral to our charity right from its beginnings back in the 1960s, when we were known as the Colostomy Welfare Group. Because of this, volunteers figure prominently in our decision making and planning. Their views and ideas help to shape the support we give. Similarly, our capacity to give support to ostomates is closely intertwined with the number of volunteers we have!

At the moment we have close to a hundred active volunteers, dotted across the country. They are all DBS checked and receive training before they go 'live'. They provide a whole array of support to ostomates. Some of them are also involved in doing things aimed at raising awareness about life with a stoma and telling people about **Colostomy UK** and the work we do.

Typically, our volunteers are involved in the following:

Helpline volunteers: Provide experience–based support to people who call our stoma helpline. Many are 'experts' in particular areas and so also speak to ostomates with specific enquiries (irrigation, reversals, travel abroad etc).

Engagement volunteers: Attend hospital and manufacturer open days, events, giving talks and presentations across the country. More recently, as **Colostomy UK** Stoma–friendly campaign has gathered momentum, some of our volunteers have been active campaigning for us in their local area.

***Tidings* and literature volunteers:** Sit on the editorial board, help with proof reading, contributing articles and review our literature.

Online forum volunteers: Act as 'admins' on our Facebook private group.

Fundraising volunteers: Support our Fundraising activities.

Trustees: Provide governance to our charity and help us develop and deliver our strategic goals.

These roles are all varied and require a range of different skills and experience to fulfil them.

Colostomy UK

call the stoma helpline for:

emotional support, experience based advice and guidance from a volunteer.

0800 328 4257

24 hours a day and completely free.

info@ColostomyUK.org Registered Charity Number: 1113471

Our help line cards have both our telephone numbers and freely distributed to support people, if you have questions, need support or just want to talk to someone who lives with a stoma.

Colostomy UK

call the adminline for:

information packs, ID cards, radar keys, travel certificates and literature.

0118 939 1537

if we're not in, just leave a message.

info@ColostomyUK.org Registered Charity Number: 1113471

Just another day at the office for Collin, one of our regular office volunteers…

What our volunteers say

As you can probably guess, one of my first jobs when I joined **Colostomy UK** as Volunteers Manager was to speak to our volunteers! I found it very interesting to hear why people had volunteered and I thought it would be good to share some of what they said. Time and again volunteers were motivated by the prospect of being able to give something back. Many felt it was a way to compensate for something that they felt was lacking in their early days with a stoma. The comment made by one volunteer: "I would have loved to have seen someone who had and lived with a colostomy", was typical of many others.

I also asked our volunteers about their experience as a volunteer with **Colostomy UK.** As the comments below indicate, this was overwhelmingly positive…so if you are reading this and thinking about becoming a volunteer yourself, then hopefully they will inspire you to get in touch and discuss our current opportunities!

> “Speaking to people at open days or on phone – can empathise and see someone go away and look a bit happier – seems worthwhile.”
>
> “Enjoy open days and speaking to people.”
>
> “Enjoy talking and giving confidence to others.”
>
> “Enjoy talking to people about issues – I had so much help and had to give something back.”
>
> “Give back –NHS saved my life – very lucky to be here.”

> “So many people don't have knowledge about dealing with stoma in an everyday way.”
>
> “Great to be trusted to the extent we are.”
>
> “Can identify problems and give something back!”
>
> “When callers realise they are speaking to someone with a stoma it is a reassuring experience for them.”

Support for Volunteers

Colostomy UK has a duty of care to make sure our volunteers are safe and equipped with the necessary skills and resources to go about their volunteering activities with us. We also have to make sure that our beneficiaries and stakeholders are assured that our volunteers are appropriately trained and recruited following best practice.

The training and support we give is regularly reviewed. If you volunteer with us, then you can expect face–to–face training delivered by a healthcare professional, as well online training covering a variety of topics. Depending on the role you will be undertaking, these might include everything from safeguarding to manual handling and lone working! Once you are ‘signed off’ we continue to support you, with regular communications and plenty of opportunities to feedback what you've been doing and get ongoing help and guidance.

I hope you have found this short insight into volunteering with **Colostomy UK** interesting. If you would like to find out more then please drop me an e–mail or give me a call. ■

..then there is Moira, ready to answer calls on our 24–hour Stoma helpline…

..here's Bernard at an open day in Poole. He likes to be out and about meeting ostomates.


Appeel
Advance
No sting
Medical
Adhesive
Remover
Spray

EHLERS-DANLOS SUPPORT UK

Ehlers–Danlos syndromes (EDS)

and/or Hypermobility spectrum disorder (HSD) and stomas

Jane Green
Area Co–ordinator
Ehlers–Danlos Support UK

Ehlers Danlos syndromes (EDS) and the closely–related Hypermobility spectrum disorder (HSD) are multi–systemic heritable connective tissue disorders. Connective tissue is the glue–like substance that is in all parts of our body. In people with EDS this connective tissue is defective. There are about 14 identified types of EDS but the most common (approximately 70% of cases) is hypermobile Ehlers–Danlos syndrome (hEDS). This is followed by vascular EDS and classical EDS. EDS/HSD sufferers vary widely in their symptoms. In some cases EDS is life limiting. At the moment there is no clear treatment pathway for the most common type (hEDS/HSD).

Both EDS and HSD are thought to be rare conditions. But it is difficult to say how rare. This is because sufferers are often not believed and can go undiagnosed. In medicine, the term 'zebra' is used in reference to a rare disease or condition. EDS/HSD sufferers are known as medical zebras. EDS/HSD can start in childhood but generally seems to trigger at puberty, pregnancy or menopause. EDS/HSD people have differing experiences and when it comes to healing of things like wound sites it is a spectrum. Some EDS/HSD People heal very well and don't tend to bruise, while people with other types have poor healing with the fragility of tissues leading to bruising of the skin following an incident or trauma. As you can probably imagine, this has implications for things like surgery. For someone with EDS it is very important that in such cases, their surgeon knows about their condition so that appropriate suturing techniques are used.

As well as having weak tendons and ligaments, people with EDS/HSD can have extra stretchy organs and/or paralysed organs. This leads to a significant number of EDS/HSD sufferers experiencing some form of gastrointestinal issue. As Laura Brockway, who was a specialist registered nurse at the Wingate Institute of Neurogastroenterology in London explains, these include: slow emptying of the stomach into the small bowel; acid reflux; bile reflux; pain and nausea. People can also suffer from uncontrollable transit or very slow transit through the bowel, as well as rectal and genital prolapses. With vascular EDS the condition can cause rupture of the bowel. In some instances the gastrointestinal issues are such that stoma surgery is necessary.

CONTINUED ON PAGE 21, MIDDLE

Win up to £25,000 with Unity

50p
From every £1 goes to Colostomy UK

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

How it works

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

How to join – three easy steps

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

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

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

If you have any queries please call our hotline on

0370 050 9240

Results & Rules can be checked by visiting

www.unitylottery.co.uk

Or by phoning the Unity winners hotline

0370 055 2291

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

Prizes	**£25,000** 6 digits	**£1,000** 5 digits	**£25** 4 digits	**5 Prize Entries in the next draw**	3 digits

1. Your details (please print in block capitals)

Title:	First Name:
Surname:	
Address:	
	Postcode:
Tel:	Mobile:
D.O.B.:	If you would like to receive correspondence via email, please tick here ☐
Email:	

☐ If you do not wish your name to be publicised if you win, please tick here

2. Payment Frequency

How many entries would you like each week? ☐

x

How often do you want to pay? (please tick payment frequency and write amount in box)			
	☐	Monthly	£4.34 Direct Debit only
	☐	Every 13 wks	£13
	☐	Every 26 wks	£26
	☐	Every 52 wks	£52

→ ☐

=

Total Payable ☐

3. Select your Payment method

☐ **Payment by Cheque** ☐ I enclose a Cheque made payable to Unity (minimum payment £13)

☐ **Direct Debit** Please fill in the form and return to **Unity**
Name and full postal address of your Bank or Building Society.

To: The Manager:	Bank/Building Society
Address:	
	Postcode:
Name(s) of Account Holder(s)	

Branch Sort Code: ☐☐ ☐☐ ☐☐

Bank/Building Society account number ☐☐☐☐☐☐☐☐☐☐

Banks and Building Societies may not accept Direct Debit instructions for some types of accounts.

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

Service User Number 4 2 1 1 0 2

Reference: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

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

Signature:	Date:

4. Your consent to Play (I confirm I am 16 or over and resident of GB) 18

Signature:	Date:

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

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

Post this form in a stamped envelope to:

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

For office use only:

T57

The Unity Lottery, Furness Gate, Peter Green Way, Furness Business ParkBarrow-in-Furness I T: 0370 050 9240 I E: info@unitylottery.co.uk
Unity is operated by Sterling Management Centre Ltd, registered as an External Lottery Manager by the Gambling Commission under the Gambling Act 2005 – www.gamblingcommission.gov.uk

The promoter of this Unity lottery is Colostomy UK, Enterprise House, 95 London Street, Reading, RG1 4QA I Registered with Reading Borough Council Registration number: LOT000141

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I hope this short article has given you an insight into EDS/HSD. At the bottom you will find the details of a number of charities that offer support to sufferers. At Ehlers–Danlos Support UK, we often speak to suffers that have had stoma surgery so I thought I would conclude with some of their comments. As you will see from the quotes on the sides, having a stoma has led in many cases to an improved quality of life. ■

"I have had my Colostomy since August 2019 and after some healing issues due to my zebra skin and a second operation, I can honestly say I am better off. I'm now no longer incontinent and my slow transit has improved slightly."

"I have an ileostomy due to slow transit. I had a temporary one in 2013 and permanent one since 2018. It's made such a huge difference to my health. I had a lot of issues healing post op but it's the best thing I did."

"I've had ileostomy since March 2019 because of EDS which caused rectal prolapses twice so it was the best decision. I'd exhausted all other options beforehand. I found the first few weeks difficult getting used to it and my body adjusting to it but now I have no issues with it and it has improved my life."

"I wasn't able to clean myself either with the natural route due to limited arm movements.

"I also don't have to worry about having accidents whilst out also. All in all I love Sid (my stoma's name) and the time he's been with me after some adjustments."

"I had my ileostomy in 2015 after having rectal prolapse for nearly two years. To be honest I was so sick by time it happened that I love it now has not made me sick! I can eat again. Yes there were teething problems and emotional things, not from me but my partner but I find it so easy now."

"I have hEDS. I had to have a stoma after my bowel perforated five years ago. For me, it was the best thing that could have happened because I had so many issues with constipation."

For further information and support:

The Ehlers-Danlos Support UK:
https://www.ehlers-danlos.org

For an example of specific local EDS/HSD support:
www.sussexeds.com

Royal College of General Practitioners Ehlers-Danlos Syndromes Toolkit:
https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/ehlers-danlos-syndromes-toolkit.aspx

Pots UK (post tachycardia syndrome):
https://www.potsuk.org

HMSA (Hypermobility Syndrome Association:
https://www.hypermobility.org

Versus Arthritis:
https://www.versusarthritis.org

References:

Laura Brockway, Specialist Registered Nurse, https://www.ehlers-danlos.org/information/gastrointestinal-problems-in-hypermobile-ehlers-danlos-syndrome-and-hypermobility-spectrum-disorders/

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, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA

Title:

Name:

Address:

Postcode:

Tel:

Email:

Please allow 30 days for delivery.

Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA   Charity No. 1113471   VAT No. 917079312   T57

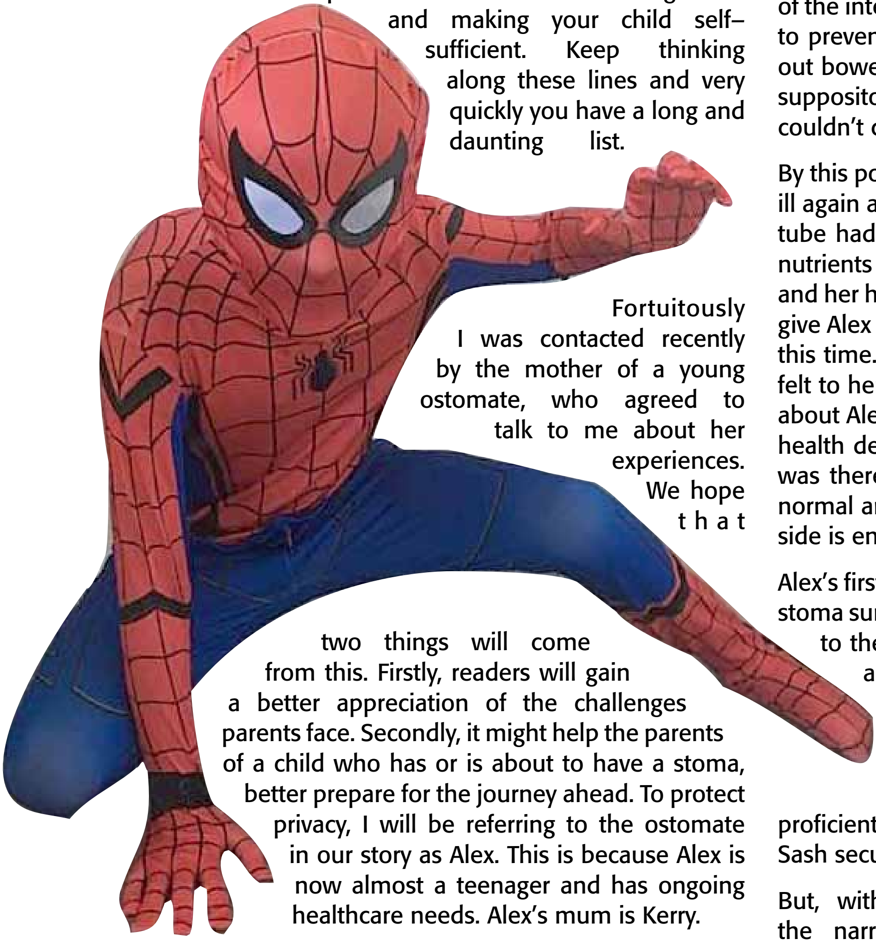
Halfx3 09v00r00 DVD Patients order form | Date of Publication: November 2019 | Copyright ©2018–2019 Colostomy UK | Registered charity no. 1113471

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

The Parents' Story

In that quiet time between Christmas and New Year I had time to flick through past *Tidings.* There are plenty of them too. Amazingly, the magazine is in its 22nd year! The thing that stood out most, was what a tough bunch of cookies ostomates are. Time and again, the articles tell of brave people wrestling back control of their lives following the trauma of illness and surgery. Something that also stood out, was the stories about young people. It reminded me that the illnesses which necessitate stoma surgery are no respecters of age. 13–year old Iolo (*Tidings* winter 2019) is a case in point.

Re–reading Iolo's story also set me wondering about something else: what about the parents? Both my children had eye surgery as tots. Two decades on, I can still remember what an emotional roller coaster it was, so goodness knows what it is like to be the parent of a child about to have stoma surgery? Beyond the obvious worry of your child being seriously ill, would be the concerns of coping with life afterwards. There would be nursery and school to consider. There would be the practical sides of stoma management and making your child self–sufficient. Keep thinking along these lines and very quickly you have a long and daunting list.



Fortuitously I was contacted recently by the mother of a young ostomate, who agreed to talk to me about her experiences. We hope that two things will come from this. Firstly, readers will gain a better appreciation of the challenges parents face. Secondly, it might help the parents of a child who has or is about to have a stoma, better prepare for the journey ahead. To protect privacy, I will be referring to the ostomate in our story as Alex. This is because Alex is now almost a teenager and has ongoing healthcare needs. Alex's mum is Kerry.

Kerry's challenges began shortly after Alex was born, six weeks premature. Still recovering from an emergency caesarean, she had to cope with him being taken from her and placed in the neonatal unit. This was because the doctors had become concerned by Alex's distended tummy and failure to pass meconium, both of which are tell–tale signs of Hirschsprung's disease. It was 13 days before Alex was able to go home. During this time bowel washouts were used and a biopsy done. Kerry still remembers how she and her husband cried with relief when the results came back negative for Hirschsprung's.

Once home, however, Alex's problems continued. At five months a further biopsy was carried out which this time came back positive. Surgery to remove the small length of intestine that lacked ganglion cells followed. These cells are needed for the intestinal muscles to move food and digested matter through the system. If they are absent then peristaltic movement cannot occur leading to constipation and blockages. Alex recovered well from the surgery, but continued to suffer. Further hospital visits revealed a narrowing of the intestine, which had to be dilated every few months in order to prevent it closing altogether. On top of this Kerry had to carry out bowel washouts and then, when these stopped working, use suppositories. These caused Alex a lot of pain and in the end Kerry couldn't continue administering them.

By this point Alex, who was nearly two years old, had become very ill again and was admitted to hospital. He was so weak that a TPN tube had to be fitted so his gut could rest and his body get the nutrients it required. At the same time, the surgeon spoke to Kerry and her husband about Alex having a stoma. In his view this would give Alex a better quality of life. It still upsets Kerry thinking back to this time. Her memories are of helplessness and barely coping. It felt to her that life was spiralling out of control; even the decision about Alex having an ileostomy was taken out of her hands, as his health deteriorated further. But the important thing was that she was there for Alex. In difficult circumstances such as these, it is normal and OK to be fearful and frightened; being by your child's side is enough.

Alex's first two years of life were traumatic but within six months of stoma surgery things started to improve. Kerry was able to take him to the local crèche twice a week where he got stuck into the activities and enjoyed playing with the other children. He put on weight and looked and felt better. The stability this brought the family was very welcome. It gave Kerry the breathing space she required to get to grips with stoma management. She and her husband became proficient at changing bags; after some research she got Alex a Sash security belt which put an end to problems with leakage.

But, with Alex still needing ongoing hospital treatment for the narrowing of his intestine, life remained demanding.

L–R: Dad, Alex, Kerry and Pooch – picture of Alex has been pixillated to protect his identity.

Kerry remembers being lonely. She made friends online with other parents of children with Hirschsprung's which helped but, unable to share the day–to–day trials of looking after a young ostomate, she still felt isolated. When Kerry said this, I thought about the situation today and whether it was any better for parents? The honest answer is 'not really'. The landscape of support remains patchy and inconsistent. That said, we are seeing some encouraging developments. Although too late for Kerry, **Colostomy UK's** JOSH helpline has been running since 2014. More recently, we have started to work with the Paediatric Stoma Nurse Group to look at other ways of addressing the issue. We are aware of some local initiatives too, such as the Gut Feeling support group I wrote about last summer. It's also the case that online support has become increasingly easy to access. Membership to our private Facebook group has risen from 1,000 in 2013 to in excess of 8,000 today (I know Kerry is a member and refers to the group as her second family). The message therefore to any parent reading this and needing support is to get in touch with us or any of the other charities that support ostomates or people with continence problems. Even if we/they can't help directly, chances are we can signpost you to the right place.

As I said at the beginning, Alex is now nearly a teenager. Although his stoma surgery in 2010 led to a better quality of life, he has required more surgery since, and treatment is ongoing. His ileostomy was closed in October 2016 and an ACE procedure carried out. Then, when this proved unsuccessful, he had a colostomy in 2018. He is now waiting for further surgery to remove his rectal stump. This can't come quickly enough for Alex; until it does he remains housebound due to the continence problems he is suffering from diversion proctitis. This has, of course, had implications for school. Indeed, school has been an ongoing challenge. First and foremost it has been difficult for Alex, with the other children asking him questions about why he is treated differently from everyone else. As any parent will know, managing these sorts of situations is difficult at the best of times, particularly the older and more emotionally aware a child becomes. But, on top of this, Kerry has faced an ongoing battle to get the right support for Alex in school. As well as encountering problems arising from general ignorance about stomas, his constantly changing needs have been an added complication. As I write this, Kerry is fighting for his Education, Health and Care Plan to be changed, since it has emerged that Alex may be on the autistic spectrum. Her hope is that Alex will be able to attend a special independent school that will support his needs as an ostomate, as well as providing an environment in which he feels safe and can begin the process of building his self–esteem and confidence more generally.

When Kerry and I spoke on the issue of school I was struck by how persistent and absolutely determined she is to fight for what she knows to be right for Alex. This has, and continues to involve, navigating processes populated with healthcare professionals, teachers, schools, social services and local authorities. Many a time she has felt exasperated and frustrated, but not once has she thrown in the towel. When I mentioned this, Kerry was keen to point out that she was only doing this because Alex deserves to be treated the same as anyone else and to have the same chances and opportunities as anyone else. Her view is that if she, or a parent in a similar situation, keeps this in mind, then there is no hill that cannot be climbed. In her words: "I will get there, but right now I'm still climbing". ■

Written by
Richard Biddle

“It’s so flexible. It just goes into my curves”

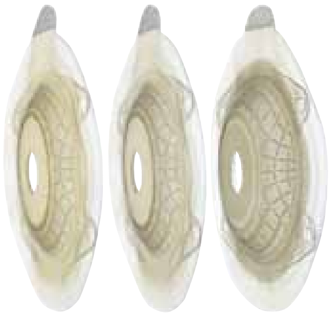
Brittany, SenSura® Mio Convex user

Coloplast

The better the fit, the lower the risk of leakage

We recognise leakage is one of the main concerns for people with a stoma. The SenSura Mio Convex is clinically proven to reduce leakage and is designed to bend with your body.[1]

Available in three unique levels of convexity, it is designed to meet your individual needs.



Soft Light Deep

With BodyFit Technology®

Our baseplates bend and stretch with the body, so they stay securely in place during movement. The inward curve of the baseplate provides stability whilst the elastic adhesive creates a reliable seal for greater security.

Yes please, I'd like to try SenSura® Mio Convex

Request your FREE sample

*By filling in the coupon, one of our product specialists will contact you to discuss which is the right solution for your needs before sending any free samples. Simply post back using the pre-paid envelope provided or send to FREEPOST COLOPLAST (no further postal address details or stamp required) and we'll be in touch. Alternatively, visit www.coloplast.co.uk/ColostomyUK

First name ____________________

Surname ____________________

Date of birth ____________________

Email ____________________

Date of Stoma Surgery ____________________

Telephone No. ____________________

Signature

How your information will be used - By providing your personal and sensitive personal data on this form, you are consenting to Coloplast Charter using it for administration and analysis purposes and to process your order. We may share this information with healthcare professionals and other companies required for the delivery of your products or as required by law. We may also contact you to ask you to clarify your requirements and to ask you to complete customer satisfaction or other surveys, and may use 3rd parties to handle this as outlined in our Privacy Policy which can be found at Coloplast.co.uk/privacy. We often keep customers up to date with the latest information on the products and services we offer. Please indicate if you would not like to be kept informed by:

Email ☐ SMS ☐ Phone ☐ Post ☐

Regulated by Care Quality Commission

*Our team are registered with the CQC (Care Quality Commission) who independently monitor the care we provide.

1. Walker et. al. Raising the bar: new flexible convex ostomy appliance – a randomised controlled trial. WCET supplement 2016

OC_ColostomyUK_Spring_Convex_19/20

Your letters and e–mails

Ed's note: Colostomy UK launched its Stoma–friendly Society campaign back in 2015 and since then we have contacted and encouraged businesses all over the country to make their toilet facilities 'stoma friendly'. Over the years we have had plenty of successes from national sporting arenas to supermarket chains. It has also been noticeable of late, that ostomates have been campaigning in their own local areas, as well as contacting bigger organisations directly about their toilet facilities. This is something Colostomy UK is pleased to support. This is why we make the stickers pictured opposite freely available and produce a set of guidelines for a stoma–friendly toilet. The letters below are from readers who have embraced our campaign.

Dear Editor

Wanted to share this…

I am a regular customer to Tesco in Barkingside, Essex and two weeks after a large part of my bowel was removed and as a new proud member of the Ostomates fraternity, I ventured out for the first time shopping, figuring that to be near to home and in as recognizable surroundings as possible, the familiarity of the whole situation would get me through this first big step.

As more practiced readers will no doubt guess, the newness of my situation and my lack of experience meant that there was no way of determining in advance when the bag needed to be emptied or replaced. Sure enough, at that time, when it needed doing… it really needed doing!!! I knew exactly where the loos were and suffice to say when I saw that sign there: 'not all disabilities are visible', I was very optimistic that disaster would be averted.

Can you therefore imagine my embarrassment, frustration and indeed distress, when at 8:30am, I went to use the disabled facility at the Barkingside store to be told that the lights for said toilet are automatic and don't come on until timed to do so at 9am – in a store that opens at 8am. To paraphrase the great Geoffrey Chaucer, 'Time, tide and full colostomy bags wait for no man'.

Luckily they had a wonderful staff member called Bhavna, who we regularly converse with and who had been following my condition for months and has family members with their own 'bags for life'. She had the presence of mind and common sense to instinctively know what the problem was and get it resolved immediately without need for embarrassing explanation. She immediately summoned the duty manager who took me to the rear of the store where I used the staff facilities.

On my return home, I wrote to Tesco head office asking the following questions:

1. Why are the lights in the disabled toilets on a different time setting to the store opening? I get it that they may have to be timed to avoid wasting electricity or whatever, but should they not be synchronised with store opening/closing? If not, why not?
2. Who looks after the disabled toilets in the staff area? Luckily my condition dictates that I rarely have to actually sit down on a toilet, but should the need ever arise for me or indeed anyone else using this, the seat was broken and could be a hazard for anyone physically less able than me.
3. You guys sell soap and cleaning materials, right? What's stopping your colleagues filling the soap dispenser in the staff disabled toilet or wiping around the mirrors? Whereas I appreciate that I was for all intents and purposes a 'guest' in a non–public part of the store, I pity your colleagues who'd have to use these toilets on a regular basis.

The last point was particularly galling – for the last 30 years I travel regularly for work and I can say, hand on heart, I have seen cleaner toilet facilities in motorway service stations in rural Vietnam than I witnessed here in deepest Essex.

This prompted the following response:

> *Dear Martin*
> *Thank you for your email.*
>
> *I am sorry for the issues you had with the in store facilities and I can understand how unpleasant this whole experience must have been for you.*
>
> *With regards to your enquires I am unsure as to why these issues have occurred but I want to make sure this does not happen again because I agree this should not happen in store and needs to be addressed.*
>
> *I have sent an email out to the Store Management team who will get these points you have raised addressed as I completely agree we cannot allow this to continue. I have also passed on your positive feedback about my colleague in store also to the Management team.*
>
> *I thank you for taking the time to get in touch and I assure you this will be looked at.*
>
> *Kind regards…*

The following week, as regular as clockwork, we went to the store at the usual time. Same issue! (I didn't need the loo – just wanted to check!!)

Spoke to the manager who vaguely recalled seeing an e–mail and told me that, believe it or not, he was at that very minute, just about to act on it. (Wow! That was a lucky coincidence!!)

Suffice to say, a few months later and everything is now as it should be.

It was all good learning…

1. Don't be afraid to speak up – in doing so you're not just helping yourself, but others in similar or worse circumstances.
2. There's no need for embarrassment – bodily functions are a fact of life. The fact that my internal plumbing is different to others is no cause for discomfort or shame.

I hope that reading this can help others as I have been helped reading the various letters in your wonderful magazine.

Martin C

Our second letter comes from a reader who wrote to Travelodge Hotels and kindly copied us in on the correspondence:

Dear Sirs

We often stay in your hotels and last week stayed in one of your newest (I believe) at Roche, Cornwall. Due to my wife's disability, we always book an accessible (disability) room.

It was very pleasant as usual and the staff were very nice and helpful, however I have decided to write to you and point out a rather small item that would make the stay even more comfortable and pleasant. I am an 'ostomate', in other words I have a stoma after major cancer surgery. I was rather disappointed that in the very nice wet room there was nowhere to hang up anything and no shelf or flat place to put my washing items, toothbrush etc and when it came to my medical items I had no choice but to put 'sterile' items on the floor whilst I changed and dressed my stoma. This could be easily remedied by a simple shelf in the bathroom or wet room.

A small unit by the bedside for tablets and water would also be very helpful.

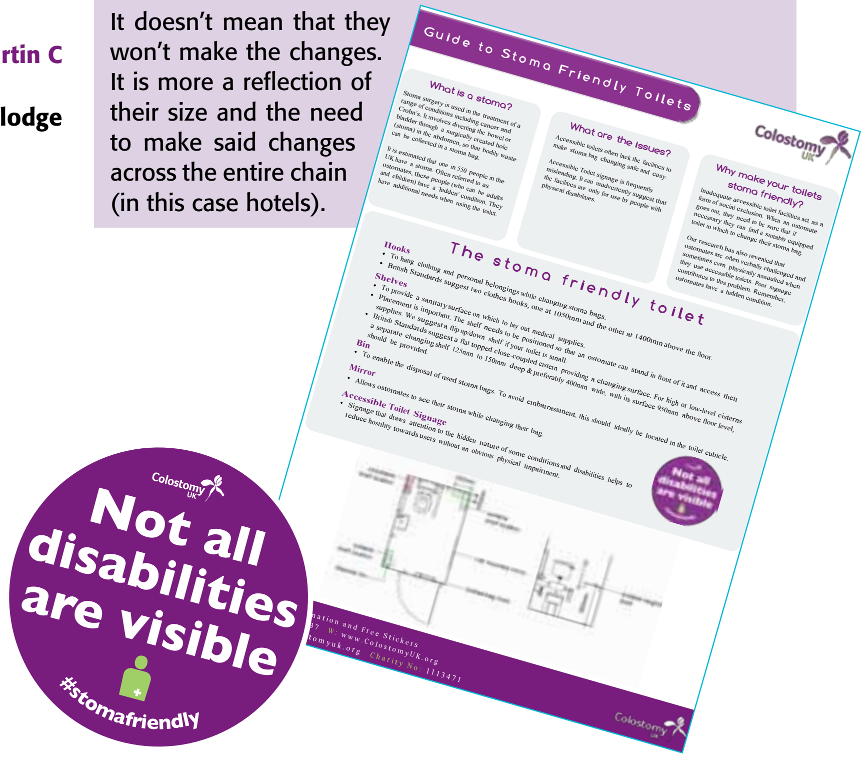
By copy of this letter I'm informing ***Colostomy UK*** *as they have been campaigning for better facilities for thousands of people like me with stomas. They have succeeded by getting improvement in toilets in supermarkets, shops, offices etc and have lead the campaign that 'All disabilities are not visible' which I am sure you have seen around.*

Thank you for reading this suggestion

Yours faithfully
John L

Ed's note: Travelodge subsequently responded to say that John's comments had been passed on to the relevant team who look after accessible bathrooms. Fingers crossed that this will lead to some changes. From our experience, it is common for the larger businesses/organisations to respond in this way.

It doesn't mean that they won't make the changes. It is more a reflection of their size and the need to make said changes across the entire chain (in this case hotels).



Guide to Stoma Friendly Toilets

What is a stoma?

Stoma surgery is used in the treatment of a range of conditions including cancer and Crohn's. It involves diverting the bowel or bladder through a surgically created hole (stoma) in the abdomen, so that bodily waste can be collected in a stoma bag.

It is estimated that one in 550 people in the UK have a stoma. Often referred to as ostomates, these people (who can be adults and children) have a 'hidden' condition. They have additional needs when using the toilet.

What are the issues?

Accessible toilets often lack the facilities to make stoma bag changing safe and easy.

Accessible Toilet signage is frequently misleading. It can inadvertently suggest that the facilities are only for use by people with physical disabilities.

Why make your toilets stoma friendly?

Inadequate accessible toilet facilities act as a form of social exclusion. When an ostomate goes out, they need to be sure that if necessary they can find a suitably equipped toilet in which to change their stoma bag.

Our research has also revealed that ostomates are often verbally challenged and sometimes even physically assaulted when they use accessible toilets. Poor signage contributes to this problem. Remember, ostomates have a hidden condition.

The stoma friendly toilet

Hooks
- To hang clothing and personal belongings while changing stoma bags.
- British Standards suggest two clothes hooks, one at 1050mm and the other at 1400mm above the floor.

Shelves
- To provide a sanitary surface on which to lay out medical supplies.
- Placement is important. The shelf needs to be positioned so that an ostomate can stand in front of it and access their supplies. We suggest a flip up/down shelf if your toilet is small.
- British Standards suggest a flat topped close-coupled cistern providing a changing surface. For high or low-level cisterns a separate changing shelf 125mm to 150mm deep & preferably 400mm wide, with its surface 950mm above floor level, should be provided.

Bin
- To enable the disposal of used stoma bags. To avoid embarrassment, this should ideally be located in the toilet cubicle.

Mirror
- Allows ostomates to see their stoma while changing their bag.

Accessible Toilet Signage
- Signage that draws attention to the hidden nature of some conditions and disabilities helps to reduce hostility towards users without an obvious physical impairment.

mation and Free Stickers
37 W: www.ColostomyUK.org
tomyuk.org Charity No: 1113471

We look forward to hearing from you, our readers:

Send an e–mail to: **info@ColostomyUK.org**

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

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

Colostomy UK: active ostomates®

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

Welcome to the regular update page dedicated to our 'Active Ostomates' project.

'Active Ostomates' supports your wellbeing with a range of programmes. Some are delivered through support groups; some can be done in your own home; others you need to sign up for. We will also be promoting activities and events that can help everyone work towards having a more active body and mind.

Rugby league update

Saturday 28th March

See the Panthers take on the Purps again!

Chisnall Playing Fields,
Chisnall Lane, Coppull
Chorley PR7 5LX

Team Colostomy UK V Chorley Panthers XIII. Kick off 13:00

North West Men's League. Chorley Panthers V Widnes Moorfield Tigers Kick off 14:45

Special guest appearances, Licensed bar, food, merchandise & much more

For more info visit colostomyuk.org

Free entry!

Following a great 2019 where we managed to increase the profile of both our charity, our rugby league team, and of what it's like 'living with a stoma', Team Colostomy UK are back in action again later this month.

Our first game of the year sees us go back to Lancashire for another game against our great supporters the Chorley Panthers. Please see above for all the game details.

It's going to be a great occasion, so if you're free why not come and cheer us on!

We'd also like to introduce our sponsors for the year. A big welcome back to SecuriCare who are our main shirt sponsors, Cheney Payroll Services, and Welland Medical, and a special welcome to our new sponsors ConvaTec. Their branding will appear on our training range. It's great to have you all on board.

We've got big plans for 2020 and we'll be announcing further matches soon so keep an eye on *Tidings* and **ColostomyUK.org**

Our games are suitable for people of all ages and abilities and we're always looking for new players. We're also looking for more people to help out on the side–lines and/or in spreading the word. Play, Support, Volunteer, there's something for everyone. Get in touch at **Giovanni.Cinque@ColostomyUK.org** or call **0118 939 1537** if you'd like to get involved.

Ready to take the plunge?

Our Active Ostomates swimming sessions are returning to Derry/Londonderry again for 2020 with Templemore Sports Complex hosting the first one of the year.

Monday 16 March is the big date. The session runs from 15:00 to 17:00. There's no organised activity or lessons, just the chance for people to get used to being in the water and having a swim in a supportive and friendly environment.

The event is free for all ostomates and their family members to attend. You just need to confirm your place in advance by contacting Chris Morrison: **chrismorrison90@hotmail.com** or call **07599 538 159.**

You don't need to take any additional steps to enjoy a swim. Your stoma bag has been designed with water in mind, although if stickers come with your stoma supplies, they can be used to cover the filter and stop it clogging in water.

We'll be adding further sessions across the UK soon.

Monday 16 March. Templemore Sports Complex, Buncrana Road, Derry/Londonderry, Northern Ireland BT8 7QL between 15:00 and 17:00.

#ActiveOstomates

Active Ostomates and Support groups

Our Chair yoga and Creative Minds art activities are proving just as popular in 2020 with support groups as they were in 2019.

With sessions already booked in for areas as geographically diverse as Glasgow, Nottingham, Bradford, Norwich, Wycombe, and Guildford, there's a good chance there's one near you!

This year we've made it easier for people to find out what's going on in their area and produced a calendar of Active Ostomates events that can be accessed online. It also includes our latest swimming sessions and Rugby League games. Just visit **http://www.ColostomyUK.org/active-ostomates/** and click on the activity you'd like to find out more about.

While all our sessions are free to participate in, we do ask that you contact the group organiser in advance. Their details are also available online.

If you run a support group and would like to join our Active Ostomate programme please email **Giovanni.Cinque@ColostomyUK.org** or call **0118 939 1537.**

Look good and support Active Ostomates while doing it!

#ActiveOstomates

Colostomy UK

Get kitted out! Clothing for the Active Ostomate

Team Colostomy UK singlet S-XL (Tight fit) £24.99 plus p&p

Team Colostomy UK Rugby League polo L-XXL £25 plus p&p

Team Colostomy UK training shirt S-XXL £29.99 plus p&p

Order online at colostomyuk.org

All proceeds support our #ActiveOstomates project

We've got a great range of merchandise for the Active Ostomate including hooded sweatshirts, hats, tee–shirts, polo shirts and more. Whether you're on the go, in the gym or on the sofa there's something for everyone.

All proceeds from our clothing range are reinvested in Active Ostomates helping us to provide more activities from swimming to chair yoga, art. Or rugby league.

See the advert on page 30 for the full range or shop online at **https://ColostomyUK.bigcartel.com/**

Revised and updated Active Ostomates: Sport and Fitness after stoma surgery booklet available.

We have distributed thousands of copies of our award winning *Active Ostomates® Sport and Fitness after stoma surgery* booklet since its launch in 2016.

To get hold of your copy either download it for free from our website, call us on **0118 939 1537** or email **info@ColostomyUK.org**

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

Supporting and empowering you

Colostomy UK

Active Ostomates®

Sport and fitness after stoma surgery

www.ColostomyUK.org

#ActiveOstomates

Freephone helpline:

0800 328 4257

24/7

TEAM COLOSTOMY UK TRAINING VEST

100% sublimated polyester featuring printed Team Colostomy UK logo & colostomyuk.org on front and #ActiveOstomates on back. Tight fitting order one size up.

£28 inc P&P

s	m	l	xl
☐	☐	☐	☐

TEAM COLOSTOMY UK BEANIE HAT

100% soft touch acrylic. Features embroidered Team Colostomy UK logo on front. One size fits all.

£11 inc P&P

Colostomy UK

Kit and Merchandise

All profits raised from the following items help us to support and empower ostomates. You can complete your order by returning the form below or visiting:

www.ColostomyUK.bigcartel.com

SIZE GUIDELINES

All clothing items are a standard fit unless stated.

Small 34/36"
Medium 38/40"
Large 42/44"
X Large 46/48"
XX Large 50/52"

TEAM COLOSTOMY UK HOODED SWEATSHIRT

Team Colostomy UK 2019 Hooded sweatshirt. Acrylic/ Cotton / Polyester mix Features printed Team Colostomy UK logo on front and #ActiveOstomates on back.

£35 inc P&P

	s	m	l	xl	xxl
Purple	☐	☐	☐	☐	☐
Charcoal	☐	☐	☐	☐	☐

TEAM COLOSTOMY UK TRAINING SHIRT

100% Sublimated polyester featuring printed Team Colostomy UK logo & colostomyuk.org on front and #ActiveOstomates on back.

£28 inc P&P

s	m	l	xl	xxl
☐	☐	☐	☐	☐

#UPTHEPURPS T-SHIRT

Show your support for Team Colostomy UK Rugby League with our brand new #UpThePurps t-shirt. 100% cotton with Team Colostomy UK Rugby League on the back. .

£18 inc P&P

s	m	l	xl	xxl
☐	☐	☐	☐	☐

Please send me the above marked items. I enclose a cheque for:

£

Payable to Colostomy UK.

All products sold individually and prices are per item and inclusive of VAT & P&P to UK and NI only. Please allow 28 days for delivery.

Title:

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Postcode:

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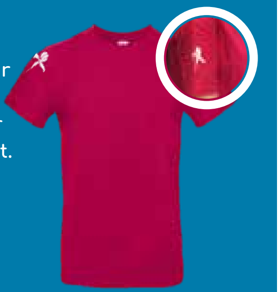
SLEEVE LOGO T-SHIRT



Stand out from the crowd and show your support for Colostomy UK in our brand new Iris t-shirt. Available in Sorbet 100% Soft spun cotton.

£14.50

inc P&P

s	m	l	xl	xxl
☐	☐	☐	☐	☐

COLOSTOMY UK T-SHIRT

Available in both purple and pink. 100% Heavy duty cotton.

	s	m	l	xl	xxl
Purple T-shirt	☐	☐	☐	☐	☐
Pink T-shirt	☐	☐	☐	☐	☐

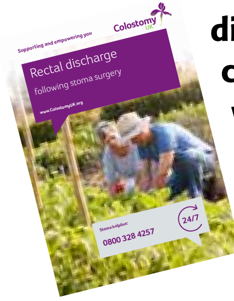
£14.50

inc P&P

You can shop online: www.ColostomyUK.bigcartel.com or mail your completed form to:
Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire RG1 4QA

Dear nurse

As readers will know, Colostomy UK produces a whole range of booklets for ostomates. These cover everything from the practical side of day–to–day stoma management to travel advice and returning to sport. Our literature titles are all available in hardcopy and can be downloaded from our website. They are used by ostomates and by stoma care nurses. In 2019, our most popular booklet was on the subject of rectal discharge (pictured left). We sent out almost 3,000 copies and the rectal discharge page on our website was visited over 8,300 times. Rectal discharge is also a common reason why people phone our 24–hour stoma helpline. With this in mind I thought it would be useful to put some often–asked questions about the issue to a stoma care nurse. I was delighted when Tina Maddams, Nursing Services Manager at Fittleworth Medical Ltd agree to help.



Supporting and empowering you

Colostomy UK

Rectal discharge
following stoma surgery

www.ColostomyUK.org

Stoma helpline
0800 328 4257

24/7

Q: Do all ostomates experience rectal discharge?

A: *No, not all ostomates experience rectal discharge. The frequency with which an ostomate has rectal discharge varies too. Some experience it rarely, such as every few weeks or so. Others can have several episodes a day.*

Q: What causes rectal discharge?

A: *The most common cause of rectal discharge is mucus. Mucus is normally found in the bowel lining and is produced to act as a natural lubricant to help the passage of stools. If your rectum and anus are still intact after your stoma surgery then you may experience a mucus discharge from your bottom. The length of bowel left after surgery is different for each person. The longer the length of redundant bowel left, the more likely that discharge will occur, as there is more production of mucus. This can be worrying, but it is very common.*

Q: What does mucus look like?

A: *Mucus can vary in colour and consistency, from a clear egg white to a thicker, sticky, glue–like consistency. It may be putty coloured. If you have had a loop colostomy then this can sometimes allow a small amount of faeces into the bowel leading to the anus. This can make rectal discharge brown. Mucus will either leak out of your bottom or build up into a ball or 'plug' which can be uncomfortable.*

Q: How can rectal discharge be managed?

A: *You may find it helps to sit on the toilet every day and push down gently as if passing a stool. This should help to remove any mucus and prevent any build–up. For some people, this is uncomfortable to do, especially if they have had surgery recently or their sensation is reduced. If this is the case, then I suggest a visit to the GP.*

Glycerine suppositories can be inserted into your bottom. These dissolve and make the mucus more watery and easier to pass on the toilet. They do, however, need to be prescribed by your GP as the frequency of use varies from person to person.

*Pelvic floor exercises have also been reported to strengthen the muscles that control the rectum. Your stoma care nurse will be able to advise.**

Supporting and empowering you

Colostomy UK

Active Ostomates®
Sport and fitness after stoma surgery

www.ColostomyUK.org

#ActiveOstomates

Freephone helpline:
0800 328 4257

24/7

*Pelvic floor exercises are also detailed in our *Active Ostomates Sport and Fitness after stoma surgery* booklet (pictured above). Call **0118 939 1537** to request a copy or visit our website to download one.

Q: What can you do to relieve the anal irritation and itching caused by this discharge?

A: *Mucus may cause itching or irritation around the anus. The use of a simple barrier cream can help to alleviate this. You may need to try several different creams to find one that works for you. Your local pharmacist can advise.*

Washing the area with plain water or using an alcohol/perfume free baby wipe will help. Dry the area by gently patting the skin to avoid friction or irritation. Apply your barrier cream.

Q: Is it necessary to seek medical advice?

A: *As I have already mentioned there are times when you should seek medical advice. In addition, you should consult your GP or stoma care nurse: if you notice blood or pus in the mucus; if you have rectal bleeding or are in severe pain; if you have excessive itching.*

Ed's note: Please keep those questions coming as we depend on them to run this feature. Any stoma–related questions that you would like to put to a stoma care nurse, surgeon, dietitian or other healthcare professional will be gladly received. You can e–mail these to editor@ColostomyUK.org or send them by post to:

The Editor, Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA

Colostomy UK: campaigns and projec

Libby Herbert
General Manager
E: libby.herbert@ColostomyUK.org

Not all disabilities are visible
#stomafriendly

We are now actively involved with the following airports across the UK: Birmingham, Bournemouth, Cardiff, Edinburgh, Gatwick, Heathrow, Luton, Manchester, and Stansted.

Together we are training, influencing and collaborating to make travel more accessible for people living with hidden conditions. There is still a long way to go, but **Colostomy UK** is now in the right places to be listened too and bring about change.

Travel Check List

On top of all the normal things, an ostomate needs to remember to:

☐ Ask the airline in advance (at least 48 hours) if you can take any extra hand luggage.

☐ Check in as early as possible to secure preferred seat.

☐ Contact the airport to get your Sunflower lanyard (see opposite).

☐ Take sufficient supplies for your stay.

☐ Take all supplies as hand luggage.

☐ Pack all your normal medications and any that may be required if your output becomes loose or you become constipated.

☐ Take with you some form of electrolyte replacement solution in case you become dehydrated.

☐ The day before you travel avoid foods and drinks that are likely to cause upset or excessive wind.

☐ Keep handy your travel certificate and other such documentation, especially when passing through immigration or security areas.

☐ Drink bottled water in foreign countries, avoid ice in drinks and use bottled or boiled water to clean around your stoma.

☐ On arrival, store your supplies in a cool place, out of direct sunlight.

Supporting and empowering you

Colostomy UK

Travel Advice

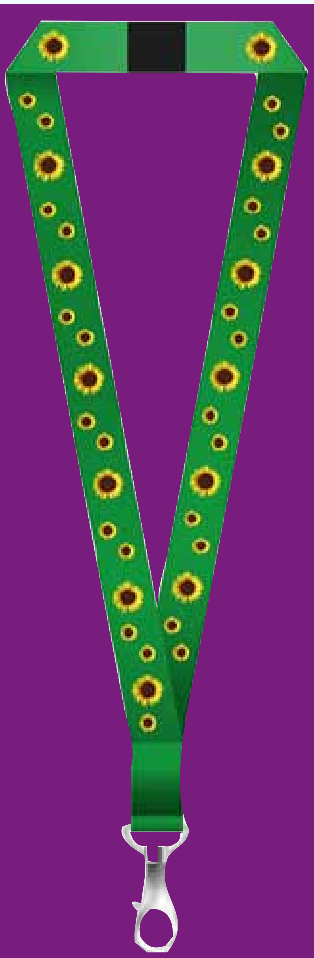
Having a stoma should not prevent you from travelling at home or abroad

www.ColostomyUK.org

Stoma helpline:
0800 328 4257
24/7

ts

#ChampionsOfAccessibleTravel



Sunflower lanyards

The use of the Sunflower lanyard (a strap that can be worn around your neck pictured left) is growing, not only is it recognised at airports but also in Marks & Spencer, Primark, Tesco, Sainsbury's, and various public transport to name a few.

The hidden disabilities Sunflower lanyard has been designed to act as a discreet sign that the wearer or someone in their party has a hidden disability and may require additional assistance or time. You do not need to pay for this lanyard or give any personal information to obtain one.

Every airport offers different options for people with hidden disabilities, please make sure you check with your departing airport for relevant information.

- You can get a lanyard by contacting the airport in advance or picking one up from special assistance on the day. You do not need to pay for it but allow at least four working days to receive one in the post.
- A sunflower lanyard shows that you might need extra support, but you will need to communicate what that extra support might be if and when you need it.
- At the airport, when travelling through security you may be able to use the family lane or special assistance lane. Where possible you will be pointed to the shortest lane or shown to the front of the queue (none of this is guaranteed).
- You will still need to go through an airport scanner. However, you can request a search in a private room.
- A member of your family can wear your lanyard if this is more suitable.
- Some airports outside of the UK may recognise the sunflower lanyard.
- Some airports have also introduced a quiet room (eg Manchester airport now have a sunflower room). This allows passengers to have some time away from the hustle and bustle of the departure area if needed.

Endorsed by Civil Aviation Authority •

ENDORSED

Travel Certificate

This photo illustrates the sorts of
supplies someone with a stoma r
them.

Please do not separate the ho
medical supplies as they may

This is what stoma

This is phot

The bag
urine.

Colostomy UK have a Tra
more information

Colostomy Association Ltd trading as Colostomy UK, registered office is at Enterprise House, 95 London Street, Reading, RG1 4QA. Registered charity number: 1113471. Company number 05623273. This certificate is in no way a medical endorsement that guarantees the holder has a stoma. It is intended to be used as an aid for airport staff.

Travel Certificate

Important information for travel authorities and their staff.

The bearer of this letter has a stoma.

What is a stoma?

A stoma is a surgically created opening in the abdomen through which the bowel and/or bladder is diverted so that bodily waste can be collected in a bag. A stoma is a 'hidden' condition.

If you need to search the bearer, then please:
· Be sensitive and empathetic.
· Offer to conduct the search in a private room.
· Do not separate the holder from their medical supplies as they may need them.
· Allow the holder a chaperone.
· Wear gloves.

NAME:

PASSPORT NUMBER:

ADDRESS:

DOCTOR'S NAME AND ADDRESS:

SURGERY STAMP:

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Stoma Helpline: 0800 328 4257
Adminline: 0118 939 1537
info@colostomyuk.org

Don't forget your FREE Travel Certificate contact our adminline:

0118 939 1537

Advice:

- If you need assistance on your flight you should advise your airline at least 48 hours before your departure date.
- You should expect to be treated the same as everyone else. Having a stoma does not exclude you from any security checks.
- You can only take more than 100ml of liquids in your hand luggage if there is a prescription label on said item.
- You can request not to go through a body scanner but if you do, you WILL be subjected to a full search. You can ask for someone to accompany you for this search.

Get your copy of our *Travel Advice* or *Travel Certificate* from Colostomy UK, write or e–mail your contact details to:

Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA
T: **0118 939 1537** | W: **www.ColostomyUK.org** | E: **info@ColostomyUK.org**

Romanian Ostomy Patients Support Foundation

and Hospices of Hope's collaboration leads to stoma care nurse training in Romania

Bob Bailey
Project Director

Despite the distance and language barriers, the last 25 years have seen UK–based ostomy support groups, working through the Romanian Ostomy Patients Support Foundation (ROPSF), forge close ties with Romania. This has been of considerable help to ostomy patients in the country. Despite improvements to healthcare during this time period, Romania remains one of the poorest countries in Europe. This can make life with a stoma challenging and provides a compelling reason for ROPSF's continued work supporting Romanian patients, their carers, nurses, doctors and surgeons.

When ROPSF began its work the situation in Romania was truly heart breaking, with patients even lacking ostomy pouches. ROPSF helped address this by sending to some of the main hospitals surplus pouches collected from UK patients, stoma care departments and appliance manufacturers. In those early years many thousands of parcels were dispatched. As you can probably imagine, just getting a few pouches was a godsend to patients. Time and again the value of what we were doing and the improvements it was making to people's lives was re–stated by the stories we heard. On one occasion an elderly man broke down in tears as he thanked ROPSF. Previously housebound, the pouches we were able to supply, allowed him to leave his home and give his daughter away at her wedding. Today, the situation is greatly improved. Thanks to pressure from ourselves and other organisations, patients now have sufficient pouches to last them from one prescription to the next, albeit that they still don't enjoy the same choice as we do in the UK.

Lack of ostomy pouches wasn't the only problem in the early years. Another was the absence of a state benefit system. With no welfare or financial safety net to fall back on, people were reluctant to seek medical help if this risked the loss of a wage earner. The prognosis for patients with bowel cancer was therefore all too often bad, leading to poor survival rates. This in turn had implications for the aftercare that was available to ostomy patients and the sorts of things that we take for granted, such as patient–to–patient support. Thankfully, much has changed and again ROPSF has been able to play its part, both in supporting patients' rights and in setting up patient support groups in several of the major surgical centres. We have also been at the forefront of encouraging greater team work between surgeons, nurses and, where possible of course, the patient.

A lack of specialist training for nurses on colorectal surgical wards is, however, an ongoing problem. This stems largely from the fact that neither the Romanian nursing body nor the Romanian department of health, recognise stoma care as a speciality. Again this is an area where ROPSF has been able to help and, indeed, develop a degree of expertise. Over the years, and with the encouragement and support of the country's more progressive colorectal surgeons, we have delivered training to many Romanian nurses in stoma care. We were therefore delighted when Hospices of Hope, a UK charity which has been working in Romania since 1992, requested our help training their nurses.

In November 2019, after much planning, the ROPSF trustees' team of senior nurses left Heathrow bound for the Hospices of Hope, Casa Sperantei Hospice in Brașov, Romania. And, thanks to a kind lady at check–in, a slightly overweight bag stuffed with stoma products for the Romanian nurses (to use both as teaching aids and in clinical practice) was allowed on board without extra cost! If that wasn't enough of a good omen, our nurses were greeted by pleasantly warm weather as they landed; a welcome relief from the freezing cold weather they had left behind in London.

The core aim of the teaching was to give the Romanian nurses a better understanding about caring for a person with a stoma. Prior to the UK team's arrival, participants completed an online workbook. The face–to–face teaching employed a variety of teaching techniques both to take into account the different ways in which people learn and to keep everyone alert during the three very intensive days. This was especially important given that both the workbook and teaching was in English. Indeed, the group of nurses was selected not just for their interest in stoma care, but

also because they possessed a good level of English language. The latter was evident when the workbooks were reviewed and certainly made life easier later on, when covering topics such as anatomy and the physiology of the gastrointestinal tract. The teaching was also supported by a Romanian nurse expert, who was able to help with translations and presentations where necessary.

The opportunity to share knowledge was made all the more enjoyable for the UK team because of the enthusiasm and willingness to interact shown by the Romanian nurses. It also helped to fill the team with confidence that the teaching they were delivering would be less likely to get lost in translation when hose attending passed on what they had learned to colleagues less proficient in English. Although the choice of stoma products is more limited in Romania as the funding differs from UK, the care needs of the patients are similar. This of course means similar demands from a nursing perspective, which again helped things to go smoothly. As you would expect, feedback received was vital in evaluating the training. Comments in the pre–course workbook included: “it was really helpful” while the face–to–face sessions were described as useful because, “I’ve learnt new techniques”. Some nurses were also inspired to learn more about stoma care “I really want to read the book and sources on–line” others felt that they had learnt more about “nutrition” and received “more information on complications” with one person rating the resources as 5✭.

There will be follow–up course in 2020, involving nurses who have an interest in stoma care but who are not so fluent in English language; indeed, it is expected that there will also be nurses from hospices in Moldova, and maybe Serbia and Albania (all of which are countries helped by Hospices of Hope). This will be a challenge…but all involved are looking forward to the next trip helping to educate the Romanian and other Eastern European nurses.

ROPSF can trace its roots back to 1995 and work started by the Ileostomy and Internal Pouch Association (at the time the Ileostomy Association), in conjunction with **Colostomy UK** (at the time the British Colostomy Association). Looking back, it is pleasing to think of the enormous progress that has been made. In 2020 patients in Romania, both young and old, are now far more likely to return to a better and more productive life after their stoma surgery than ever before. However, there is still much more to be done before Romanians enjoy the level of aftercare standards achieved in Western Europe. By the time you read this article a new Romanian patients’ website will have gone ‘live’ which we hope will be another step towards removing those feelings of ‘being alone’ by providing a mechanism through which patients can share their thoughts and experiences. More recently ROPSF has been encouraged by the Romanian Ambassador in London talking about the need to conduct research, looking at the ‘Quality of Life’ for those in the country with a stoma. Our hope is that such a project might lead to ROPSF facilitating a collaboration between a UK and a Romanian university. Without doubt, research of this nature would have the potential to benefit enormously patients and their carers in the country. But, of course, such a project needs funding. If you feel able to offer even a little financial support ROPSF would be deeply grateful.

Romanian Ostomy Patients Support Foundation is a registered charity in which the trustees all give their time for free. But the charity can only exist and help others with sufficient funding. As such we need financial support if we are to continue to survive and serve the less fortunate ostomy patients in Romania. You can make a donation by post: **Romanian Ostomy Patients Support Foundation, Forest Lodge, Glenmore Road, Crowborough, East Sussex, TN6 1TN,** or by electronic bank transfer: Sort Code: **60 06 27** Acc Number: **51638495**

Pictures top and above of Braşov, Romania – Courtesy of the Romanian Tourist Board, London

Thinking about the religious and cultural needs of stoma patients

Lisa Hall
Community Stoma Nurse
Salts Healthcare

I would like to start this article by stating I am in no way a religious expert, vicar or any other type of faith leader. I am simply a community stoma nurse with a personal interest in different cultures and I am particularly keen to explore the impact that practising a particular faith may have on a person with a stoma.

Working as a community stoma nurse brings many challenges, especially in a multicultural city such as Bradford. Approximately five years ago, my colleague and I were faced with questions relating to patients wishing to participate in Ramadan. That particular year happened to be a glorious hot summer, and Ramadan was taking place in June which included the longest day. Ostomates would be fasting for approximately 16–18 hours depending on when the sun set. We couldn't find any evidence to either prohibit or recommend fasting in stoma patients therefore we set about asking our existing patients what they did and gained advice and tips along the way. This resulted in a patient education leaflet (top right) that is now available nationally every year for patients and stoma nurses to use as a guide. The advice we give is to only participate if you are currently well and haven't recently had surgery or undergoing chemotherapy. Stop fasting at any time if you develop symptoms of dehydration. Change your pouch daily to check that your stoma is still healthy and active as usual. During the hours when eating and drinking are allowed, try to avoid salty or fried foods as this can make you feel thirstier later on. Try to get two litres of fluid in any form possible, not just water. Have smoothies or juices made from fruit and vegetables to rehydrate whilst maintaining a healthy intake of vitamins and minerals. This helps avoid constipation in colostomy patients and prevent dehydration. The leaflet is provided in English, Arabic and Urdu and is available from Salts Healthcare.

I have always had a fascination for learning about other faiths and cultures and the Ramadan piece of work fanned the flames and increased my thirst for knowledge in this area. Many years ago when I did my general nurse training (not quite Florence Nightingale times but not far off!), we didn't have any formal training regarding faith. Spirituality and exploring how a person practises their beliefs was certainly touched upon, but more to acknowledge it than to dig deep into.

After discussing Ramadan with my patients, I decided to look at other faiths and specifically, how there may be implications in stoma care. I found all of my patients were keen to share their knowledge and happy to answer my questions which ultimately helped me to learn so much more than I expected.

Stoma nurses give advice about all aspects of recovery and convalescence from surgery, not just about how to care for your new stoma. We discuss diet, hygiene, clothing, getting back to work and resuming a sex life and it is important that we think outside of the box and include cultural implications. If we look at hygiene, we need to remember that the Hindu religion prefer to use running water rather than a bowl of water for cleansing. Muslim patients carry out a specific hygiene ritual five times a day before prayers and stoma care needs to be incorporated into this. Jewish ladies undergo a ritual immersion bath at their synagogue following menstruation and wearing a stoma bag can be seen as a barrier by some. The travelling community have a separate building for washing and cleaning that is away from the toilet area, and the stoma nurse will be aware to ask each person if there any specific rituals or cultural issues that we need to be aware of when teaching stoma care.

Diet can be a complex issue for many ostomates and is a subject that often causes concern. Muslim and Jewish people don't eat pork and the Sikh and Hindu community don't eat beef and are predominantly vegetarian. Whilst this doesn't necessarily cause a huge problem, we need to discuss that certain foods can cause more wind or loosen the output. Beans, pulses, nuts and seeds are very difficult for many people to digest leading to some ostomates omitting them from their regular diet. For a vegetarian or vegan patient, that would be difficult as pulses are a main source of protein.

Some stoma flanges and medication have gelatine as part of the ingredients and this would not be acceptable for Muslim, Jewish or vegan patients. Loperamide (Immodium) can be taken as a syrup or tablet rather than a capsule and there are

medilink

Helping you celebrate Ramadan

We know how important Ramadan is to many of our patients. So we've pulled together some advice to help you participate. Don't forget, fasting isn't obligatory if you are elderly, sick or it would be detrimental to your health. If you do decide to take part, here are some top tips to make it go as smoothly as possible:

WHAT TO EAT

AVOID SALT

If you have a urostomy or ileostomy, you may be at a higher risk of dehydration. Salty, processed or fried foods can be difficult to digest and can make you feel more thirsty.

CONTROL OUTPUT

Avoid foods that make your output loose or give you wind, such as leafy green vegetables, very spicy foods, baked beans and too much fish. Ileostomists may be able to take loperamide during non-fasting periods.

WHAT TO DRINK

STAY HYDRATED

Drink at least 2 litres of non-fizzy water or caffeine-free drinks when not fasting. If you have a urostomy, introduce foods that are high in water, such as melon or cucumber.

INTRODUCE JUICES

Juicing fruits and vegetables can be a good way of getting the health benefits and extra fluids if you are unable to eat whole pieces of fruit and vegetables

OTHER HINTS AND TIPS

KEEP COOL

If the weather is hot, try to stay cool and don't exert yourself too much. Try to keep out of direct sunlight.

DELAY FASTING

Patients who have recently had surgery may be excused from participating. Discuss his with your Imam or mosque leader and if you can 'make up the days' after you completed your recovery.

CHANGE REGULARLY

Change your bag daily to check the health of your stoma. It's important to ensure your stoma is pink, red and moist.

WHAT IF I BECOME UNWELL?

Stop fasting and contact your GP. If you are concerned about any of these issues or how your stoma may be affected, please speak to your local hospital, GP or Stoma Care Nurse for more information.

itten by Salts Medilink® Stoma Nurses Lisa Hall, RGN; and Sarah Ashworth, RGN, able input from their patients.

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RM765586 02/19

Halal and vegan options for jelly babies which we often recommend to thicken a loose stool. I have spoken to a Rabbi and an Imam who have both stated that if there is a medical reason for a medication, dressing or stoma bag, then this would be allowed and not forbidden on religious grounds. Some stoma companies have recently started to explore the ingredients in the stoma flanges and are manufacturing ones that do not contain any animal derivatives at all which is a huge step forward.

We site pre–operatively for a stoma wherever possible to avoid waistband on clothing and creases in skin etc. I also ask my patients who pray in a prone position, to show me how they do this when I am siting for a stoma. It is important to see the shape of the abdomen in all positions in order to avoid marking in an inappropriate place wherever possible. It is vital for a person who is devout and wishing to return to their place of worship that they feel comfortable and safe to do so. The Islamic faith forbids any faeces, urine or flatus to be expelled when inside the mosque which can make it difficult for anyone with a stoma to attend. Obviously wearing a clean bag before attending mosque is easy to achieve however nobody can stop a stoma from working when it wants to. Filter covers can be worn to stop the flatus from escaping during prayers and any concerns can be discussed with your stoma nurse or Imam. Many people are concerned about returning to their place of worship, what if the bag leaks, smells or makes a noise?

These are the same fears that most people have when returning to work or leisure activities, as stoma nurses we are happy to discuss these concerns with all of our patients and will help wherever possible.

Communication is essential for nursing staff and patients and a language barrier can cause misunderstandings and confusion. Hospital staff have access to translators or the phone translator system in outpatient clinics, but working alone in the community is very different. Whilst family members can often translate for us, it may not always be appropriate to use that method. An elderly lady would not be happy to discuss rectal discharge or stoma output via her 12 year old grandson I'm sure and there are also concerns that some information may not be relayed correctly. We use DVDs, photographic step–by–step guides and demonstrate using stoma appliances. In the past, WWW translate has helped where necessary and there has recently been a language line facility available to patients using certain delivery companies. This has been very useful for the patient, nurse and delivery company staff to ensure they are placing an order for the correct products. Some members of the travelling community cannot read or write so we must not rely on patients being able to take away leaflets or look at information we leave for them to read after we have visited.

Caring for stoma patients who practice different Faiths has been a huge privilege and massive learning curve for me and I continue to learn every day. ■

Readers may be interested to know that **Colostomy UK** took advice on this issue back in 1987. Abd Allah Abd–Alkalik Al Mishad, the then Chairman of Fatwa Commission of AL–AZHAR University responeded as follows:

> *"In answer to this question, we reply that whoever is in such a situation is considered to have a religiously legitimate excuse. Since a stoma patient cannot replace the pouch for each prayer, he may perform absolution at the onset of each prayer interval.*
>
> *He may then pray as many times as he may wish during this prayer interval.*
>
> *At the onset of a new prayer interval, the absolution performed in the last interval is no longer valid and the stoma patient should perform a new absolution for the new prayer interval and so on (for each of the five prayer intervals).*
>
> *Allah, Glory to be him is more knowledgeable than all."*

First Signature
Chairman of Fatwa Commission
of AL–AZHAR

Abd Allah Abd–Alkalik Al Mishad
8 Jumada 1, 1407
8 January 1987

Colostomy UK: focus on fundraising

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

Why should you fundraise for Colostomy UK?

Colostomy UK is a self–funding charity. We receive no statutory support and so rely on donations to fund our activities. This means that every penny that you fundraise for us is vital. Without your help, we couldn't support and empower ostomates or be their voice on the bigger issues.

Why Gift Aid isn't boring!

The next hundred or so words that you read may not convince you that Gift Aid is the greatest thing since sliced bread but hopefully it might make you realise how important it is to a charity like **Colostomy UK.**

Here's a really straightforward example of how Gift Aid works. Imagine every time you got paid your employer added an extra 25% to your salary…how amazing would that be? And what if that 25% came at no extra cost to your employer as well? Everyone's a winner!

In essence that's how gift aid works. If you donate £30 to us and tick the Gift Aid box on the donation form (see page 40) we can claim an extra 25% or £7.50 from HMRC. It doesn't cost you anything and provides us with more funds to focus on the things that matter to you, such as providing support through our stoma helpline, producing this magazine, campaigning for stoma–friendly toilets, or getting more ostomates up and active.

So if you're a UK tax payer and would like to make a donation to **Colostomy UK,** please remember to tick the Gift Aid box. It really does make a difference.

Help us to make a difference

Doing something amazing is about the people that you help, not the challenge you take on. You don't need to climb Everest to fundraise for **Colostomy UK.** You can bake a cake, hold a tea party, or organise a sponsored walk.

A successful event doesn't need to raise huge amounts of money either. Our fundraising pack is full of ideas to help get you started. If you would like a copy just call us on **0118 939 1537** or e–mail **fundraising@ColostomyUK.org** Thank you!

Stoma 66 Fundraisers

A number of people who took part in our Stoma 66 challenge last year also took the opportunity to fundraise for **Colostomy UK** as well as getting active. So far we've raised over £9,000, so a huge thank you to everyone who fundraised for us and donated.

We'd also like to take the opportunity to highlight three people who are all taking on fantastic challenges for **Colostomy UK** this year.

On 11 April Lydia Compton–James along with her friends Ami, Raychel and Jenny, will be taking on the Yorkshire Three Peaks challenge. Lydia's wife had stoma surgery following gastroenteritis and they're hoping to raise as much as possible to help us to support more ostomates in the future. You can make a donation at this link **www.justgiving.com/fundraising/lydia-compton-james1**

You may remember Emma Raynes from previous editions of *Tidings.* This year she is aiming to reach Everest base camp in support of **Colostomy UK,** while running a few marathons as a warm up! October is the month that matters and we'll be following her progress all the way. If you'd like to support Emma please visit her Just Giving page **https://www.justgiving.com/fundraising/emma-raynes10**

Last, but definitely not least…Colin Reynolds is planning two traverses of the Lake District in April and October. You can support Colin here **https://www.justgiving.com/fundraising/coloriginaltraverse**

Text giving

Colostomy UK

To donate £1, text ColUK001 to 70201

To donate £5, text ColUK001 to 70970

To donate £10, text ColUK001 to 70191

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

We've recently launched a new Text Giving service. It's a quick and easy way to donate and help us to continue producing *Tidings,* our advice literature and all our projects and campaigns.

The amount you donate will be added to your mobile phone bill, or deducted from your pay as you go credit. You will receive a reply confirming your donation.

Unity Lottery

Members have the chance of winning a main prize of **£25,000** each week (plus a £2,500 donation to **Colostomy UK**), as well as smaller prizes of five free draws, £25, and £1,000. Entry is only £1 per week and we receive 50p for every £1 ticket sold. You can join by completing the form on page 20 or online by visiting: **www.unitylottery.co.uk** Just remember to link to **Colostomy UK!**

Legacy

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

What your gift means

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

- Ensure there is always a voice at the other end of the phone.
- Train volunteers to provide support at open days and in hospitals.
- Help support our 'Stoma Friendly Society' campaign, our 'Fight the Poo Taboo' campaign and our projects including 'Active Ostomates'.

How to leave a legacy

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

Your solicitor will need the following information on our charity:

Name: **Colostomy UK**

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

Charity Commission registration number: **1113471**

After you have provided for your loved ones we hope you will consider a gift to **Colostomy UK.**

YOUR WILL, YOUR LEGACY

Colostomy UK

USING YOUR WILL TO HELP OSTOMATES OF TODAY AND TOMORROW

Make a donation

Colostomy UK

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

My Details: Title: Forename: Surname:

Home address:

Postcode:

Telephone (home): Mobile:

Email:

Date of Birth: Month and year of operation:

Reason for your stoma: Stoma type: ☐ Colostomy ☐ Ileostomy ☐ Urostomy

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

I would like to receive information about: ☐ Tidings magazine ☐ Bag and product manufacturers ☐ Colostomy UK, the work it does, including training, conferences, volunteer opportunities and fundraising.

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

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

I would like to make a donation of:

☐ £20 ☐ £30 or whatever you are able to give £

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

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

Card number (Maestro only)

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

Signed Date D D M M Y Y

giftaid it Thank you for your gift

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

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

Signature: Date: / / 2019

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

To the Manager: (Bank or Building Society)

Bank Address: Postcode:

Name(s) of Account holder(s):

Account number: Sort code:

I would like to make a regular donation* of ☐ £20 ☐ £30 or other amount (please state) £

☐ monthly ☐ quarterly ☐ annually starting on the ☐ 1st ☐ 15th ☐ 25th of month: year:

thereafter until further notice. (Please cancel any previous standing order in favour of this beneficiary).

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

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Name: (IN CAPITALS)

Signature: Date: / / 2020

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

Registered Charity No: 1113471

Registered with FUNDRAISING REGULATOR

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

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 e-mail: info@ColostomyUK.org

Cornwall Ostomy Support Group

The Cornwall Ostomy Support Group welcomes all people who have a stoma or have had a stoma reversal. We meet the first Tuesday of every month at Carnon Downs village hall, near Truro, from 02:00pm to 04:00pm. We also run a quiz night every third Wednesday of the month at the same venue. The start time is 07:00pm.

On 11 December we held our Christmas lunch at the Falmouth Hotel. Once again it was a great success with 54 members attending. If you would like to find out more about us, then contact **Ken Jones: 01872 863 106** or visit **www.cornwallostomysupport.org.uk**

Stevenage Ostomistics Open Day

We will be holding an Open Day on Saturday 30 May 2020 from 10:00am to 01:00pm at the Oval Community Centre, Vardon Road Stevenage SG1 5RD. As well as manufacturers and distributors being present, there will be talks from a dietitian and from a nurse about skin care.

Refreshments will be available and there is ample free parking at the venue. For those who use public transport, Bus **no 2** to St Nicholas departs every 12 minutes from **Stand G** at Stevenage bus station and stops at the Oval.

We would love to see you there!

To find out more about Stevenage Ostomistics contact **Judy Colston: 01438 354 018 neilcolston@btinternet.com**

Stoma Life East Kent – New FaceBook Support Group

We at Stoma Life understand that everybody has their own story, and everyone has different abilities. We are all at various stages of our lives, either living with, or supporting a loved-one with a stoma. With this in mind, we welcome you to give positive support, share your experiences, and give your supportive words of wisdom that you've gained through your life with a stoma.

I hope that creating a regional group will bring all ostomates (old and new) altogether as a community in east Kent; a place we can find information regarding local support groups and be notified when product supply events, charitable events and maybe in the future a once a year county event bringing our region together.

We encourage you to engage with our community and be an active member of Stoma Life, for your benefit, and for the benefit of others ❤. If you know of anybody that lives in east Kent and would benefit from this group please feel free to invite.

To access the group in FaceBook, search for: **Stoma Life East Kent**

Supporting and empowering you

Colostomy UK

Looking for online support?

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

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

We look forward to welcoming you.

www.ColostomyUK.org

Stoma helpline:

0800 328 4257

24/7

Stoma care open days

Attending a stoma care Open Day is an opportunity to find out about all the ostomy products and services available. It is also a chance to meet other people who have a stoma and visit the charity stands to talk to people who can give you advice and support.

Colostomy UK volunteers, all of whom either have or have had a stoma, attend stoma care Open Days all over the country whenever possible. Do come along, call at our stand and have a chat.

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

Coloplast Event
Bromley Court Hotel, Bromley Hill,
Bromley, BR1 4JD
11 March 2020 10:30–13:30
Sam Fenton: gbsfe@coloplast.com
or 07721 261 654

Stoma Care Information Afternoon
MacMillan Wellbeing Centre,
Moorside Road, Urmston,
Manchester, M41 5SN
18 March 2020 13:30–16:00
Stoma Care 0161 746 2323

ConvaTec Roadshow
Mercure Telford Centre Hotel,
Telford, TF3 4NA
15 March 2020 10:00–16:00
ConvaTec: 0800 834 822

Musgrove Hospital
Stoma Care Open Day
Bridgwater & Albion Rugby Football Club,
Bath Road, Bridgwater, TA6 4TZ
31 March 2020 10:00–15:30
Stoma Care Department: 01823 342 453

Coloplast Event
Mercure Nottingham Sherwood,
296 Mansfield Road,
Nottingham, NG5 2BT
2 April 2020 11:00–14:00
Coloplast: 0800 220 622

West Suffolk Hospital Ostomy Open Day
Red Room at Tattersalls, Newmarket,
Suffolk, CB8 9AY
23 April 2020 10:30am–14:30
Katie Lloyd & Ann Hubble
on 01284 712872

Countess of Chester
Stoma Care Open Day
Ellesmere Port, Masonic Hall,
141 Chester Road, Ellesmere Port,
Cheshire, CH65 6SD
29 April 2020 13:00-16:00
Stoma Care Dept: 01244 366 170

Coloplast Event
Bentley Hotel, Newark Road,
Lincoln, LN6 9NH
30 April 2020 11:00-14:00
Coloplast: 0800 220 622

Coloplast Event
Avington House, Avington, Dorchester,
Winchester, SO21 1DB
6 May 2020 13:30–16:30
Terry Anne Horncastle:
gbtah@coloplast.com or 07770 494 727 or
Julie: gbjtu@coloplast.com or
07469 144 186

Salisbury District Hospital
Annual Stoma Care Open Day
Guildhall, Market Square,
Salisbury, Wiltshire, SP1 1JH
20 May 2020 14:00pm–16:00
Come along on the day

Coloplast Event
Casa Hotel, Lockoford Lane,
Chesterfield, S40 7JB
21 May 2020 11:00am–14:00
Coloplast: 0800 220 622

To get your open day added to our website and included in *Tidings* please e–mail **info@ColostomyUK.org** or call our admin line **0118 939 1537.**

National support organisations

IA The Ileostomy and Internal Pouch Support Group
www.iasupport.org
Telephone: 0800 0184 724
e–mail: info@iasupport.org

UA Urostomy Association
www.urostomyassociation.org.uk
Telephone: 01386 430 140
e–mail: secretary@urostomyassociation.org.uk

Mitrofanoff Support
www.mitrofanoffsupport.org.uk
Telephone: 07903 382 013
e–mail: info@mitrofanoffsupport.org.uk

Purple Wings
www.purplewingscharity.com
e–mail: lauren@purplewingscharity.com

IOA International Ostomy Association
www.ostomyinternational.org

Junior Ostomy Support Helpline (JOSH)
via the Colostomy UK 24–hour free helpline: 0800 328 4257
e–mail: info@ColostomyUK.org

Breakaway Foundation
www.breakawayfoundation.org.uk
Telephone: 01283 240 253
e–mail: info@breakawayfoundation.org.uk

Bowel Cancer UK
www.bowelcanceruk.org.uk
Telephone: 020 7940 1760
e–mail: admin@bowelcanceruk.org.uk
Email Bowel Cancer UK nurses:
nurses@bowelcanceruk.org.uk

Macmillan Cancer Support
www.macmillan.org.uk
Telephone: 0808 808 0000
Monday–Friday, 9am–8pm

Crohn's and Colitis UK
www.crohnsandcolitis.org.uk
Telephone: 0300 222 5700
e–mail: info@crohnsandcolitis.org.uk

The IBS Network
www.theibsnetwork.org
Telephone: 0114 272 3253
e–mail: info@theibsnetwork.org

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

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 e–mail: info@ColostomyUK.org

Stoma support groups
in your county

Channel Islands

Guernsey
Guernsey Ostomates
Luci Deane 01481 236 077 / lucideane58@gmail.com

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

England

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

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

WAMS (Windsor, Ascot, Maidenhead & Slough) Stoma Support Group
If you are interested in joining then please e-mail wamsstoma@gmail.com or call 01189 391 537

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

Buckinghamshire
High Wycombe Stoma Support Group
0800 318965

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

You Are Not Alone Stoma Support Group
Carla 07846 354 918 e-mail: carlawright0502@gmail.com

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

Cheshire
Countess of Chester Hospital Stoma Support Group
Stoma Nurses 01244 366 170

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

Warrington Ostomy Support Group
Louise or Joan on 01925 454 813

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

Co. Durham
Bishop Auckland Stoma Care Group
Mrs Maureen Davison 01388 818 267
email: rdavidson816@gmail.com

Darlington Support Group
Margaret Clothier, telephone number 0191 333 2184

Durham Stoma Support Group
Lynn Ridley 0191 333 2184

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

Cornwall Ostomy Support
Ken Jones: 01872 863 106 or www.cornwallostomysupport.org.uk

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

Cumbria
Grange Cancer Support Drop in
Marie O'Connor 01539 533 279

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

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

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

Mercia Inside Out Stoma Support Group
Sally Chester 07500441442; Jackie 07919002612; Gary 07779218245

Devon
Devon IA
Martin Hornby: 01458 251 095 or email: devon@iasupport.org

Mid Devon Ostomy Support Group
Janice - janice234ford@gmail.com or tel: 0792 3975051 or 01884 799369

Plymouth & District Bowel Cancer Support Group
Wendy Wilson - Facebook: Plymouth Bowel Cancer

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

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

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

Essex
Connect
Lin Hart 01279 505 273 email: comeconnectwithus@gmail.com

Mid Essex Stoma Support Group
Paul Foulger: 01245 224 374

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

Optimistic Ostomates
Angela Taylor 01702 385 510

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

STEPS - Stoma Essex Patients Support
01268 451 937 or email- stepsessex@gmail.com

Hampshire

Replummed stoma support group
www.replummed.me

Solent Ostomates Support Group (S.O.S.)
For information tel. 07527 707 069 or solentostomates@hotmail.co.uk

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

The Hampshire Ostomates Support Group
Contact Nicki Beare on 07771 558 458 or email: Hampshireostomatesgroup@gmail.com

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

Wessex Urology Support Group
Mrs Jo Stacey: 07910 786 978

Herefordshire

Herefordshire Stoma Support Group
Carol Steele 01432 880 656 or email: carolsteeleglo@gmail.com

Hertfordshire

Ostofriends Stoma Support Group (Potters Bar)
ostofriends@gmail.com or call 07596 748 376

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

Isle of Man

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

Isle of Wight

Optimistics
CNS's Sarah Capon & Sarah Varma
01983 534 009

Kent

Ashford Stoma Support Group
Carole Hobbs: 01303 814 014

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

Dartford Ostomy Group Support (DOGS)
Tracey or John: 07779 155846 or 07948 974 350 or dogs-uk@hotmail.com

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

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

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

Maidstone Stoma Support Group
Judy/Kirsty: 01622 224 305

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

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

Thanet Stoma Buddies Support Group
Kathy 01843 291 825

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

Lancashire

Kangaroo Klub, Blackpool stoma support group
For further details please contact the stoma department at Blackpool Teaching hospitals,
01253 956 620 or e-mail
crc-stomanurses@bfwhospitals.nhs.uk

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

Oldham Stoma Support
June Wilde: 0161 312 5538

Phoenix Bowel Cancer Support Group
Sandra Peet: 01772 683 790, www.phoenixgroupbvh.com or eMail: sandrapeet7@aol.com

Leicestershire

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

Lincolnshire

Grantham Support Group
Bobbie/Rachel: 01476 464 822

London

Bowel & other Cancer Support Newham
020 8553 5366

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

Newham Stoma support group
Contact Lauren King 020 7055 5576

Rectangle - Colorectal Cancer Support Group
Regina Raymond 020 7472 6299

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

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

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

Merseyside

Bowel Cancer and Stoma Support Group (BeCauSe Group)
For further details please ring 07948 120 955

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

St Helens Cancer Support Group
Denys Floyd- 01744 884 097

Middlesex

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

Norfolk

James Paget Ostomy Support Group
Sandra Hutchings: 0150 258 5955

Kings Lynn Ostomy Friendship Support Group
For more info please call 01553 775 698 / 01553 674 962 / 01553 768 271

Norfolk Ostomates Support Group (on Facebook too)
Barbara Harris 01603 417 046 / 07789 581 312

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

Northamptonshire

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

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull: 07714 479 320

Hexham Ostomy Group
Judith on 07967 927 286

Northumberland Cancer Support
members@northumberlandcancersupportgroup.co.uk

Nottinghamshire

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

Nottingham QMC Stoma Support Group
Rosemary Brierley: 0115 982 6691

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

Shropshire

B.O.T.S. (Bums on Tums)
Irene Constable on 0169 123 8357

Somerset

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

Staffordshire

County Stoma Group
Moira Hammond 07788 402 195 / cm.hammond@ntlworld.com

Outlook The North Staffs Ostomy Support Group
Moira Hammond 07788 402 195 or e-mail: cm.hammond@ntlworld.com

Suffolk

East Suffolk Ostomy Group
Marion Fisher: 01473 311 204

James Paget Ostomy Support Group
Sandra Hutchings: 0150 258 5955

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

Surrey

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

Normandy Colostomy Support Group
Robin Young robin.young11@btinternet.com 01483417610 Website: http://www.normandystomagroup.wordpress.com

Stoma Support Group
Robin Young: 01428 723 255

Sussex

Brighton & District Support after Stomas (SAS)
Sylvia Bottomley: 01273 554 407

Chichester Stoma support Group
The Stoma Care Team 01243 831 527

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

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

Tyne and Wear

Gateshead Stoma Patient and Carer Support Group
Stoma Care Nurses: 0191 445 3152 or email stuart.sutcliffe81@yahoo.com

NHS Molineux Support Group
John Burchell 0191 265 1047

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

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

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

Warwickshire

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

West Midlands

Birmingham, IA
Michael Jameson 0121 355 2745 / 07842 555 070 See also: https://birmingham.iasupport.org/events

Coventry Stoma Support
Martin - 07947 385 643

Wiltshire

Swindon IA
www.swindon-ia.org.uk

Wessex Stoma Support Group
Karen Barryman 01980 590 599 or 07799 863 766
Email: info@wessex-stoma.co.uk
Website: www.wessex-stoma.co.uk

Worcestershire

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

Yorkshire

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

Airedale Stoma Support
Sue Hall: 01535 646 373

Barnsley Bottoms Up Stoma Support Group
Stoma Nurses 01226 4325 28 or Celia Utley (Chairman) 01226 284 262

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

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

Bradford Stoma Support Group
Lisa Hall 07552 276747

Dewsbury & District Stoma Support Group
June 07884 003 945 or email dews.ssg@gmx.com

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

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

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

Scarborough Stoma Support Group
Stoma Care Team: 01723 342 388

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

Northern Ireland

County Antrim

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

Colostomy UK Volunteers Northern Ireland
Chris Wright: 07720 717 771

County Armagh

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

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

County Down

North Down Stoma Support Group
Adrian Ewing on 07850 741 511

Ulster Hospital
Hazel/Martina: 028 9055 0498

Londonderry

Causeway Support Group
Mary Kane: 028 7034 6264

Republic Of Ireland

County Mayo

Mayo Stoma Support
Marion Martyn: +353 94 902 1733

Dublin

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

Scotland

Ayrshire

Ayrshire & Arran Stoma Support Group
Hugh Strathearn: 07837 464 376
Email: hstrath@aol.com

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

Fife

Fife Ostomy Support Group
Ishbel Barr: 01592 772 200

Lanarkshire

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

Moray

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

Scottish Borders

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

West Lothian

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

GOSH (West Lothian)
Scott Pattison: 07502 163 644

Wales

Aberystwyth

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

Bridgend

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

Carmarthenshire

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

Conwy

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

Gwent

Blaenau Gwent Self Help
Celia McKelvie: 01873 852 672 After 6pm

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

Mid Glamorgan

C.A.S.S Colorectal and Stoma Support Group
Chair person 01685 877 144

Pembrokeshire

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

Powys

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

Rhondda Cynon Taf

Royal Glamorgan Stoma Care Support Group
Domenica Lear 01443 443 053

Swansea

Swansea Ostomy Self Help Group
Glynis Jenkins: 01792 418 245

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Ostomy Female underwear. Shortie or brief with built-in internal support left, right or twin pocket with night drainage.
Sizes 8-24. Colours: black or white

Unisex seamless support briefs, providing appropriate light post-operative support. Sizes S/M - 2XL/3XL. Colours: white, beige or black

Female seamless support briefs, providing appropriate light post-operative support. Sizes S/M - 2XL/3XL. Colours: white, beige or black

Ostomy Male underwear. Trunks with built-in internal support left, right or twin pocket with night drainage. Sizes: Small - XXL. Colours: navy or denim

Ostomy Male underwear. Boxers with built-in internal support left, right or twin pocket with night drainage. Sizes: Small- XXL. Colours: navy or white

* Please ask about VAT exemption if you have a permanent stoma

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