Winter 2018 | Issue 48

Colostomy UK

Tidings

Aled Griffiths receives The British Citizen Youth Award

Happy New Year from Colostomy UK

Coloplast

Introducing Coloplast Care

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Coloplast®
Care

The Ostomy Check

Coloplast® Care

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

Please tick in circles where appropriate

Do you have any adhesion issues?

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

○ *None* ○ *Insufficient adhesion when applying* ○ *Adhesive dissolves during wear* ○ *Adhesive edges roll*

Do you have any skin irritation issues?

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

○ *None* ○ *At the outer edge of the baseplate* ○ *Under the baseplate* ○ *Around the stoma*

Do you have any pouch issues?

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

○ *None* ○ *Leakage* ○ *Odour* ○ *Ballooning or pancaking*

For two piece appliance users only

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

○ *None* ○ *Coupling difficult to close or open* ○ *Pouch falls off* ○ *Leakage at coupling*

How is life with a stoma making you feel right now?

I am having a difficult time ○ *1* ○ *2* ○ *3* ○ *4* ○ *5* ○ *6* ○ *7* ○ *8* ○ *9* ○ *10* I feel great

First Name
Surname
Address
Post Code
Date of birth (DD/MM/YYYY) D D M M Y Y Y Y
*Email
Date of Stoma Surgery D D M M Y Y Y Y
Telephone Number
Signature

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

From time to time we do let people know of new products or services which may be of interest by phone, email or post. By submitting your information to us, you consent to us contacting you in this way unless you have indicated that you would prefer for us not to contact you by ticking the box below.

Please do not contact me by: Post ☐ Email ☐ Phone ☐

CA-Care-Jan17

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

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

Gill

*What is **Coloplast® Care?***

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

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

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

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

Alternatively you can take the Ostomy Check and sign up to Coloplast Care at **www.coloplast.co.uk/ColostomyUK**

Coloplast

Coloplast® Care

dear READERS

A Happy New Year from all of us at Colostomy UK!

I hope that you've all had a peaceful Christmas and haven't already let those New Year resolutions slip. 2017 was a very busy, but hugely successful year for our charity. Rebranding as **Colostomy UK** helped impress that we are now more than just a patient association, but led to a frantic couple of months over the summer. This included building a new website, updating our literature and telling people about our ever expanding mission to support and empower ostomates.

On the campaigns and projects front we made great strides forward. If you have managed to keep up-to-date with *Tidings* and our website, you'll know that as a result of our stoma friendly toilet campaign a number of sporting venues, shopping centres and other visitor attractions adopted our new signage stickers. In April we joined the UK Toilet Consortium and are hopeful that in 2018 this will prove effective, lobbying local and central government for change. In October we ran our annual Colostomy Day. Last year we celebrated **#superstomas** using the day to raise awareness of how stoma surgery can save and improve lives. Events were held up and down the country, and we also got lots of exposure on social media. Project wise, Active Ostomates saw the roll out of chair yoga and archery to support groups across the country. The accompanying leaflet *Active Ostomates: Sport and Fitness after stoma surgery* was also highly commended at the British Medical Association (BMA) Patient Awards. Stoma Aid had a successful second year too, collecting and sending out consignments of surplus bags to developing countries.

Our team of volunteers were very active as always, attending open days and events across the country. It was because of them that our helpline remained open every minute of every day in 2017, providing vital help and support to ostomates and their carers. We also saw well over a thousand new ostomates register with us, along with many more joining our closed Facebook support group. If you are someone that enjoys social media then you will have probably noticed that in 2017 **Colostomy UK** enjoyed a bigger profile than ever before. We now engage with lots of younger ostomates through blogs, nearly 2,000 people and organisations follow us on Twitter and we have had six articles published by *Huffington Post*.

For me, Libby , the icing on the cake was the charity's 50th Anniversary celebration. Being new to the role of General Manager and new to the whole ostomy world, it was fantastic to meet and talk with people face-to-face. I learnt a lot too, which will help me in 2018, as I prepare for another, equally successful year!

Libby
General Manager

Sarah
Trustee, Colostomate and Volunteer

e-mail editor@ColostomyUK.org

Cover picture
Aled Griffiths receives The British Citizen Youth Award. L–R Ashley Banjo, Aled Griffiths and Lauren Thomas. Find out more on pages 11 and 12.

How to contact Tidings

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or write to the address below.

Advertising enquiries
For a media pack and advertising rates
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or telephone 0118 918 0500

To request (or cancel) your quarterly copy of Tidings
e-mail info@ColostomyUK.org
or telephone 0118 939 1537

Postal address
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NEW

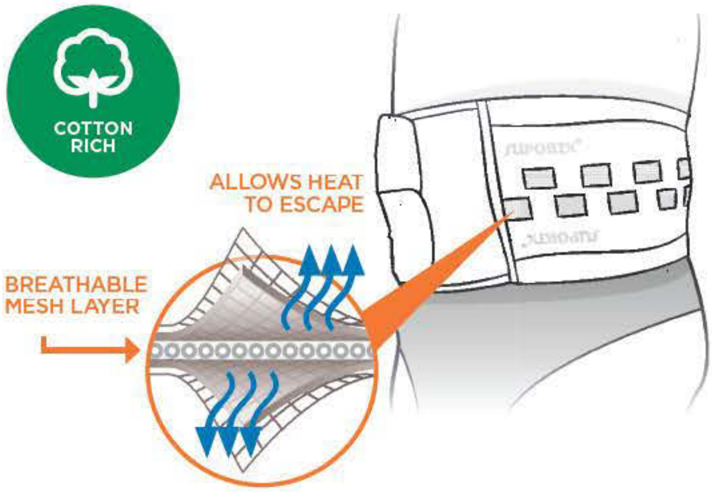
SUPORTX™

Breathable Easy Peel & Tube Belts

The Breathable Easy Peel Hernia Support Belt has been developed to provide abdominal support for a variety of hernias which include ostomy, parastomal, umbilical, epigastric and abdominal scars.

The anti-roll silicone pattern on the elastic bands help prevent the belt from rolling offering exceptional ease of use and comfort.

The belt helps immobilise the stoma pouch or hernia during daily activities whilst providing discretion and a smooth appearance. Furthermore, the belt helps to dampen the noises from the stoma pouch.



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☎ **0800 917 9584** **www.suportx.co.uk**

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all your regulars & special features

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Colostomy UK News

Living with a Stoma

From Health Professionals

Real Lives

Support

How to get in touch with Colostomy UK

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

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

How to become a supporter of Colostomy UK

Simply contact us by post:
Colostomy UK
Enterprise House, 95 London Street
Reading, Berkshire, RG1 4QA

By telephone:
General Enquiries: 0118 939 1537

Stoma care queries only:
24–hour free helpline: 0800 328 4257

By E–mail:
info@ColostomyUK.org

Find us on FACEBOOK:

Find us on Facebook

Join our 'closed' 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!

Visit us and register at:
www.ColostomyUK.org

Don't delay Donate Online today!

There are **NOW two ways to donate online**

①

Visit the **Colostomy UK website** and **simply click** on the **donate panel** on the **home page.**

JustGiving ②

Visit the **Just Giving home page** you will see a search panel **'Find a Charity'** type in **Colostomy UK.**

Colostomy UK

Colostomy UK is a charitable company limited by guarantee (Registered Charity No: 1113471).

Bulletin Board

Libby Herbert, Colostomy UK General Manager with Clive Proctor from Sainsbury's Redhill

Sainsbury's to install shelves and hooks in all accessible toilets

After a year of discussions with Sainsbury's, we are delighted to announce that this leading supermarket chain is the first in the UK to commit to making all their accessible toilets stoma friendly. The first store with the new facilities is in Redhill, Surrey.

A nationwide roll–out begins in 2018. Along with ensuring that every accessible toilet will have a shelf and a hook, Sainsbury's are changing all their signage to promote the fact that not all disabilities are visible.

Supporting ostomates at Manchester Airport

In November 2017, we visited Manchester Airport to participate in a disability forum. The focus of the day was to enable charities to input into the customer experience at the airport. We also met with the security and training team from the Manchester Airport Group (MAG) who were keen to work with us to resolve the growing number of complaints we have received from ostomates on the security process. Demonstrating their clear commitment to supporting ostomates' needs, the team from MAG met with us in December last year to plan training for both their security and customer service staff.

Helpline Training

In October, we held volunteer helpline training in Birmingham. 17 volunteers attended, a mix of new and those wanting a refresh. We would like to thank Salts Healthcare who sponsored the day and allowed us to use their training academy to host the event. With the support and advice we are able to give via the helpline, it's vital that everyone that takes calls is fully trained and kept up–to–date.

Helpline volunteer training

Active Ostomates Booklet 'highly commended' by BMA

We are delighted to announce that our booklet: **'Active Ostomates: Sport and Fitness after stoma surgery'** was 'highly commended' at the British Medical Association (BMA) Patient Information Awards on 18 September 2017. The judging panel commented that it was 'an excellent resource which should do well'. This prestigious event, which is held each year, aims to support and encourage patient–centred care through the production and dissemination of accessible, well–designed and clinically balanced information. Trustee Ian Jackson and Dr Richard Biddle, our writer and researcher, attended on behalf of **Colostomy UK**.

Volunteer Retirements

We would like to thank the following volunteers who are retiring this year. Without our volunteers we would not be able to support as many ostomates as we do and we are incredibly grateful for the time and support our volunteers give to us.

Tom Reid from Dundee joined us as a volunteer in 2006, in 2013 he was made Volunteer Area Organiser. He managed a small team of volunteers and organised our presence at open days across the region. He has represented us at the Scottish Stoma Forum and at many events in Scotland, travelling all over the country for us. We are very grateful for the support that Tom has given us and he will be greatly missed as a volunteer.

Roger Barrett from Doncaster has been a volunteer for over 35 years. He has been our area organiser since 1988 and has been very active, representing us at open days and providing helpline support. He has also provided support in his local hospital and for stoma care companies. Roger has been an amazing volunteer and his support and commitment will be hard to replace.

ASCN Annual Conference 2017

Thank you to Association of Stoma Care Nurses (ASCN) for hosting such an informative and well attended event. We were very happy that so many nurses took the time to visit our stand. Like us they realise that ostomates benefit when we work together. The event was highly successful for the charity in other ways too. We were thrilled to present a talk on how we can support nurses and their patients and explain how our campaigns and projects empower ostomates once they have recovered from surgery. We look forward to ASCN 2018. ■

Jo McKenzie, Morag Sinclair, Sarah Squire and Ian Jackson on our stand at ASCN 2017


Now Sterile
Now Sterile
SOS
LBF

Aled Griffiths

By **Richard Biddle**

L-R: Ashley Banjo, Aled Griffiths, Lauren Thomas

The British Citizen Youth Award was set up in 2016 to applaud acts of bravery, kindness and compassion carried out by young people in the UK and to recognise their contribution to society, charities and good causes.

We were delighted that, amongst this year's 24 medallists, was our very own Aled Griffiths. Aled was born with VACTERL association, which led to him having a colostomy formed when he was just two days old. At the age of seven he underwent what is known as the ACE procedure as well as a bladder augmentation and a mitrofanoff. Aled has been involved with Colostomy UK since 2015 when, at the age of 11, he became our Children's Ambassador for JOSH. As you can see from the pictures overleaf it was a fun, but prestigious event, with the medallists going to the House of Lords to receive their award. Aled's parents Gaile and Neale, along with Jo McKenzie from the Colostomy UK team, went to help him to celebrate the day.

THE BRITISH CITIZEN youth AWARD

Language Crib sheet

We do not have 'Winners' we do have 'Medallists'

People do not 'Win' a BCyA – they are 'awarded a BCyA' or are 'selected to receive a BCyA' or have a 'BCyA bestowed upon them'.

They do 'receive a specially struck medal of recognition inscribed with the words For the Good of the Country'

Individuals 'are recognised for their positive impact on community or society'

Individuals 'are role models in their communities'

Individuals are 'invited to use the BCyA letters as post nominals'

We do not have an 'Awards ceremony' – we have a 'formal presentation at the Palace of Westminster'

Individuals do not 'enter the awards' – they 'are nominated for recognition'

The purpose of the BCyA programme is to recognise individuals that are making a positive contribution to their community, society or chosen cause, in the hope that it encourages them to continue and others to emulate their good deeds.

It is important to the BCyA that young people are recognised as widely as possible for the good that they do, to help change perceptions of young people often portrayed negatively in the media.

BCyA recipients are all extraordinary young people from across the country who have a commitment to improving the lives of others. They come from all over the country to be honoured at The Palace of Westminster.

Any young person under the age of 16 can be nominated for a BCyA. The programme represents multi-cultural Britain welcoming nominations for any child that is committed to making a positive impact on their community or their chosen cause.

Nominations are now be welcomed for the 2018 medal presentations, for a nomination form contact jacquif@britishcitizenawards.co.uk with BCyA in the title.

Kind regards

Mike Faulkner
THE BRITISH CITIZEN YOUTH AWARD
Group Director

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I recently caught up with Aled, hoping to find out a little more about the young man behind the award. To be honest, I wasn't really sure what to expect. At age 14, he already has a rather imposing curriculum vitae. As an ambassador for **Colostomy UK** and Mitrofanoff Support UK he regularly gives talks and presentations (to healthcare professionals, families, children, schools), using his own story to inspire others to achieve their goals – no matter what life throws at them. This has taken him as far afield as the USA and has even included an appearance at Wembley! If that wasn't enough, he has also walked the catwalk at a couple of fashion shows and 'done' television. Not many people of his age can boast sharing the 'Green Room' with the likes of Paula Abdul, The Vamps and Bruce Dickinson.

BCyA Official Presentation Guide 2017

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VACTERL association In medical terms, an 'association' is a group of symptoms that appear together more often than would be expected by chance. VACTERL is an acronym made up of the first letters of the main symptoms that make up the condition: vertebral defects, anorectal anomalies, cardiac defects, tracheo–oesphageal fistula, renal abnormalities, limb abnormalities (Great Ormond Street Hospital for Children, http://www.gosh.nhs.uk/medical-information/vacterl-association).

Richard from Colostomy UK: Thanks for finding time in your busy schedule to talk to me. I know that many of our readers won't have heard about VACTREL association, so maybe you could start by telling me a little about how this affects you day–to–day?

Aled: Sure, it affects lots of things including everything from dealing with buttons and getting dressed to sitting down, going to the toilet and cutting with scissors.

Richard: But I know this hasn't prevented you from being active. I understand you've even helped build a school!

Aled: Yes, I won a place on a scholarship trip with the charity 'Me to We'. In August 2016 I travelled to Udaipur in India as part of a group of thirty 12 to 18 year olds, where together we helped to build a school in a rural community. It was a great experience and I was able to manage my stomas.

Richard: So, tell me a little about the work you do. It takes some guts to get up and talk to large groups of people. What inspires you to do it?

Aled: I don't get as nervous as I used to. I do it because I want to spread awareness about the challenges people face but, at the same time, I want to show that being disabled shouldn't stop you doing things.

Richard: Well that seems like as good a set of reasons as any! Staying with same subject, what do you consider to be your greatest achievement?

Aled: I'm very proud of the British Citizen Youth Award that I received last autumn. Another great moment was when I got to speak to 12,000 people at Wembley.

Richard: Let's talk a little more about you 'the person' now. What does the future hold for you, what do you want to do as an adult?

Aled: Well, I want to go on and study psychology and hopefully criminal psychology, because I would like to become a crime scene investigator. I enjoy those sorts of programmes on T.V. and I'm very interested in the reasons that bad people do what they do.

Richard: Interesting, I think I'm going to have to be careful… What sorts of things do you do in your spare time?

Aled: I go to explorers and I also go rifle and air rifle shooting. I've been doing shooting for 12 months now. I have managed a perfect 50/50 score with the air rifle and my best score with the rifle is 92/100. My new year's resolution is to push this up to a 97.

BCyA 2017 Medalists with Siblings, Great Hall

Richard: umm… I can see that I'm definitely going to have to watch my step! We'll finish with some quick fire questions if that's ok? Here we go…

Harley Davidson or Porsche? Porsche.

Group Shot Terrace House of Lords

McDonald's or Burger King? McDonald's. But I'd prefer TGI's over both of them because of their 'Pulled Pork Sunday'.

Justin Timberlake or Justin Bieber? Neither (Eds: Good answer, Aled!)

What celebrity would you like to have dinner with and where? It would either be Bella Thorne or Zendaya Coleman and I would take them to the 'all you can eat' at Za Za Bazaar in Bristol.

What one thing would you like your Mum to stop doing? Nagging me.

As I hope you can see from our interview Aled, despite his impressive résumé, is anything but imposing. Instead he is warm and engaging, which is probably the secret of his success. He is also (and I'm sure he won't mind me saying this) a typical teenager. So, well done Aled for your recent award, it is thoroughly deserved and everyone at **Colostomy UK** is grateful for your hard work promoting awareness and showing that having a stoma need not be a barrier to leading an active and fulfilling life. ■

Junior Ostomy Support Helpline (JOSH) was launched in late 2015, with the aim of providing help and support to the parents and carers of children with bowel and bladder dysfunctions. JOSH was championed by the late Wendy Hetherington (one of our trustees). It was through Wendy and her contacts at Mitrofanoff Support UK that Aled's parents first came to learn about Colostomy UK.

ACE (Antegrade Colonic Enema) procedure An operation where the appendix (or a section of bowel) is brought out through the skin to form a very small conduit stoma. This forms a channel into the bowel which can be catheterised to introduce water and a stimulant to wash out the bowel.

50th Anniversary Open Day and Fashion Show 2017 Report

Our 50th Anniversary Open Day on 16 September 2017 was attended by over 300 people and, as we hoped, it was a huge success. As well as being able to see the latest stoma care products, attendees could book a one–to–one session with a SecuriCare stoma nurse. There were also a number of talks throughout the day, which covered everything from our history as a charity to the latest news about Stoma Aid. In the afternoon we were joined by Mr Neil Smart (consultant colorectal surgeon, Royal Devon & Exeter Hospital) who gave a very informative presentation on parastomal hernias. During the evening meal we were able to make 'Outstanding Contribution' awards to **Ernie Hulme** (trustee) and **Rosemary Brierley** (former editor of *Tidings*) for everything that they have done for us over the years. We were also pleased to announce the Stoma care clinic at King George's Hospital as 2017 winners of the coveted Purple Iris Award.

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All in all, it proved a wonderful way to celebrate half a century of helping people like you. It was also the perfect time to announce our change of name to **Colostomy UK** and tell everyone about all our exciting plans for the future.

But don't take our word for it, just read what a representative from one of the 17 stoma care companies in attendance had to say: "What a perfect day for patients and companies alike, I spoke with many patients about their experiences, and we learnt from each other and our life experiences". These sentiments were echoed by the ostomates that came along, as new friends were made, acquaintances renewed and exhibitor stands visited. Some people were even brave enough to say hello to the team from **Colostomy UK**. When asked what they had liked most about the day, one person remarked "Everything!", another pleaded with us to "keep going!".

So, we would like to say a big thank you to everyone that came along and for all the kind wishes we received from those that couldn't make it. We were also very grateful for the sponsorship we received from Coloplast, ConvaTec and Dansac. It was Dansac that made the evening fashion show possible and, as we expected, this was a great hit. Many said afterwards that it had been 'inspirational'. We couldn't agree more. As our ostomate models strutted the catwalk, donning everything from formal attire to sports kit and beach wear, the message was clear: ostomates can, and do, live life to the full.

The pictures below capture the essence of the day and the fun that everyone had. ■

Surviving the unsurvivable

The statistics of my hospitalisation run as follows:

Nine months in total, four months in intensive care, six weeks in an induced coma and then 20 laparotomies, five plastics operations, one tracheostomy, one skin graft, endless procedures to insert lines into my chest, neck and arms. A couple of epidurals. The removal of the spleen, the loss of all bar eighteen centimetres of the large bowel, some of the small bowel and a section of pancreas. A dose of Discitis for good measure. One deep vein thrombosis and the addition of a colostomy. Not to mention the loss of the tip of the middle finger and the reconstruction of the right hand.

I was there because I had been filming the correct way to deploy safety flares and one of the brand new flares that I had fired had been faulty. It backfired through my hand and lodged in my abdomen, where it burned for 60 seconds at 3000ºC.

I have written a lot about the accident and subsequent recovery and talk frequently at events and to medics. I call the talk, "Just a Sharp Scratch", after that business everyone goes through before they stab you with a needle. "Here we go, Just a Sharp Scratch". It's rubbish of course, it invariably hurts. And if you are going to have an injection get a nurse to do it. You'll hardly feel a thing. With a doctor you'll have a bruise for weeks. Just a sharp scratch, still I suppose it's better than what they used to say which was: "Just a small prick".

But this piece is not about the humour that you squeeze out of catastrophic events just to help you get through them, this is about what happens when you have survived. When the operations are over, the medics have moved on and you have to come to terms with a new life, a life perhaps with some disability, a life with a colostomy.

You can sit there feeling sorry for yourself and of course we all do a bit of this at some point, or you can get on and get out there. You hear stories of colostomates who used to do a little light hill walking, who after their colostomy climb Everest every day...before breakfast.

I can't say that I have been as extreme as this but I certainly have re–invented myself since the accident, or do I mean moved on in life. Before the accident I was a voiceover actor, a Royal Yachting Association instructor and I had my own sailing school. Today, 11 years later, I am still a voice over actor, although I do far less than before but I also managed

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CONTINUED FROM PAGE 15, COLUMN 3

to become a features writer for the yachting magazines. I have written two books – *Stress Free Sailing* and *Stress Free Motorboating* – and am working on a third – *Stress Free Navigation* – and I have created a safety product – MOB Lifesaver – which fits into a lifejacket and allows an incapacitated casualty in the water to be recovered on board a boat. I still sail my 35 foot yacht, single handed and still teach navigation.

Of course having a colostomy, going to new places is always a strain. At home or on my boat all is well but invite me round for supper and immediately I am worried about having to change at your house. Or suggest we go to a restaurant and again I am edgy. By now of course I have changed my bag in just about every location possible – in the car in a layby, in a field, in the ladies loo, in underground car parks, behind a hedge at the Isle of Wight Festival with 80,000 people looking the other way, thank goodness Simple Minds held their attention and no one looked round. It's never easy and there is always that fear in the back of the mind of getting caught out, having to make a sudden change in the most inconvenient place.

But that apart, the system seems to work OK. I don't appear to have lasting difficulties from my other injuries. Using chopsticks at the Chinese is out as I am missing the tip of the middle finger on my right hand but that is no hardship because despite being reasonably adept at chopsticks in the past, I never found it a very satisfactory way of eating a meal. You can get a decent mouthful on a fork, but I've never managed this with chopsticks!

I do have some fairly pronounced herniations but after investigation it has been decided that going back into my abdomen to correct them would cause more issues than not. In fact the surgeon who normally offers a 5% chance of things going wrong with his herniation work, gave me a chance of less than 5% of things going right and advised that we leave the subject alone.

What I have to do is to try not to put too much weight on. Never easy.

There is one side effect of all this that I have discovered, which will affect others I am sure and that is deafness. Not just the deafness associated with old age but deafness associated with medication, specifically certain antibiotics. Having accused the family of mumbling and lack of articulation and having endured their retorts of 'Deaf git!', I went for a hearing test. And sure enough, severely deaf in one ear and moderately deaf in the other. The audiologist asked if I had ever had any of the following and reeled off a list of medicines. When he got to Vancomycin, I stopped him. "Oh yes, they used to give that to me regularly in hospital. I had several bouts of sepsis and that was what they used, lots of it I seem to remember." And that apparently is the reason that I am going deaf. Being 63 won't help I don't suppose but any antibiotic with 'Mycin' is known for causing deafness. It kills off the furry bits in the ears that detect sound – something like that. In fact they use it strategically. if someone is suffering from incurable dizziness, which comes from the ear they can turn the ear 'off' with Mycin and render it deaf to cure the dizziness, the audiologist told me. Fascinating what you learn. So if anyone has been on any of the 'Mycin' antibiotics they can reasonably expect to have an early onset of deafness. With my lovely new hearing aids I can hear a mouse thinking, or a man scraping leaves in Brussels. I get a lot of high frequencies. Still I can hear a little better.

So, if you are sitting there thinking, how on earth you are going to manage with your new colostomy, while I can't take it away I can let you know that others manage, I manage. I have an excellent life in fact, just as long as I make sure that all dinner parties are held at my house. And I am glad I survived what they have all called an unsurvivable accident.

Duncan Wells

Photo ID Card

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

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

- **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 10–14 days for delivery.

Previously issued cards will still be valid.

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

IDENTIFICATION CARD

Disability Rights UK

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

123e45

To obtain a **key or a photo identity card** please **complete the form and declaration.** Make your **cheque payable** to the **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 make a credit card payment, please contact the admin team at the **Colostomy UK** office via the following methods: Telephone: **0118 939 1537** or Email: **info@ColostomyUK.org**)

National Key Scheme - Key and photo ID card purchase

Title:

Name:

Address:

Postcode:

Tel:

Email:

Please **tick** as appropriate:

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

☐ I would also like to receive a **photo ID** card for a charge of **£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.

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 disabled toilet facilities. The key is for the personal use of the above named and their designated carer only.

Signature of self or carer: Date: / /2018


I WANT TO BE HEARD

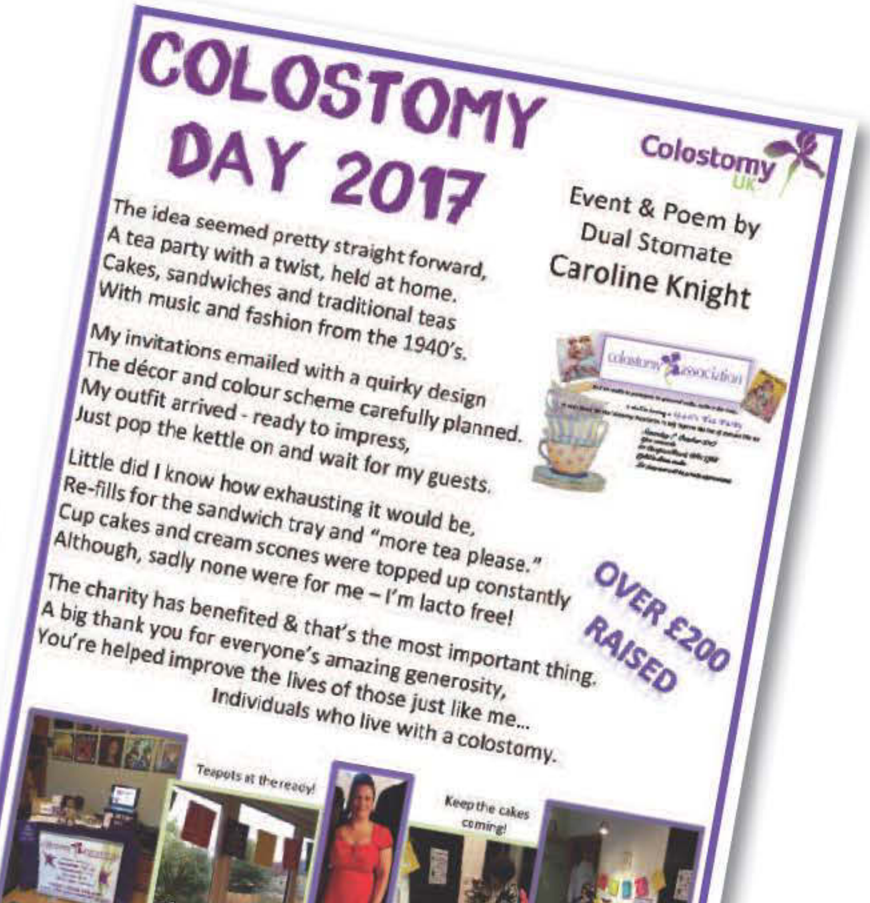
COLOSTOMY DAY 2017 #SUPERSTOMA

Thank you to everyone that took part in Colostomy Day on 7 October. This year we celebrated super stomas and raised awareness of how stoma surgery saves and improves lives.

Across the country and on social media people held events, took part in activities and shared their stories and photos to show how their stoma made a positive impact on their life.

In Derry, Northern Ireland, Chris Morrison led a huge team of people all donned in Colostomy Day t-shirts around the local park run. In Tesco in Salisbury the Wessex Stoma group held a coffee and awareness morning. The C–Side Colorectal Cancer Support

Chris Morrison and his team taking part in Park Run, Derry



COLOSTOMY DAY 2017

Colostomy UK

Event & Poem by
Dual Stomate
Caroline Knight

The idea seemed pretty straight forward,
A tea party with a twist, held at home.
Cakes, sandwiches and traditional teas
With music and fashion from the 1940's.

My invitations emailed with a quirky design
The décor and colour scheme carefully planned.
My outfit arrived - ready to impress,
Just pop the kettle on and wait for my guests.

Little did I know how exhausting it would be,
Re-fills for the sandwich tray and "more tea please."
Cup cakes and cream scones were topped up constantly
Although, sadly none were for me – I'm lacto free!

The charity has benefited & that's the most important thing.
A big thank you for everyone's amazing generosity,
You're helped improve the lives of those just like me...
Individuals who live with a colostomy.

OVER £200 RAISED

Teapots at the ready!

Keep the cakes coming!

Coordination was key!

Group in Brighton held a Cocktails and Mocktails party. Caroline Knight held a 1940's tea party at Stovell House PPG.

Stoma Care companies joined in as well with Welland Medical holding superhero themed activities in the office with directors dressed as superheroes.

On social media many of you got involved to help get **#superstoma** trending. (A trend on Twitter refers to a hashtag-driven topic, like **#superstoma** that is immediately popular at a particular time, in this case on Saturday morning.) You shared photos of your stoma bag, some with super hero masks on, and shared your story of how your stomas saved your life. For many of you this was a big step and a brave thing to do, so thank you. On the day itself, over 23,000 saw our tweets and retweets.

On our blog, we shared inspirational stories from Abi, Shell, Sarah, Ian, Ashley and Maria. Each one demonstrating that without the lifesaving surgery things would be very different.

On these pages are photos from the day and more will follow on our website. Keep an eye out for our plans for 2018 and thank you again for helping make Colostomy Day 2017 such a huge success.

Julian Whitehouse

@ColostomyUK Celebrating 4 months with my #Superstoma today. #Stomaversary #colostomyday #OstoMATE

The C-Side Colorectal Cancer Support group Cocktail and Mocktails event


MOULDS AROUND YOUR PROFILE

Readers' writes

Do you have a story to tell, experiences or concerns to share with other ostomates, issues to raise? Maybe you have comments and suggestions about *Tidings*.
Write in or e–mail us today. The editorial team looks forward to hearing from you.

Sarah Squire

Dear Editor

I would just like to share my experience with you as it may help others who have had similar difficulties.

My operation was in 2013 after my bowel ruptured. I initially had great difficulty in emptying the pouch when using the toilet in a conventional manner. There was no tuition given by hospital staff after the operation and one was left to muddle through as best one could. I still muddled through but getting on in years made me think of an alternative way of emptying the pouch.

My first thought was to have a special toilet basin installed to allow access to the pouch when seated. However I soon realised that this was not the best solution. The method I use and found very satisfactory is to sit on a stool at toilet level facing towards the basin. This I find the most easy way of emptying the pouch. I purchased a stool which could be adjusted to the height required for home use and should I travel I use a lightweight collapsible seat. I find public toilets with disabled facilities very useful and user friendly when using the collapsible seat.

Bob Crabtree

Dear Editor

My husband had a sinus after a resection of the anus due to bowel cancer and it just never healed. Dressed daily by myself it often became infected and was constantly weeping and bloody. Because of my husband's other health problems (compression of spinal cord then a year after the bowel cancer operations) the surgeon was reluctant to reopen the wound. After many conversations he did agree. Four years on and four months ago he reopened the wound. He went very deeply into the tissue and discovered a hair deep in the tissue was growing inwards. The surgeon had never seen it before. My husband came home and we had the district nurse daily – again the wound was absolutely horrendous, so raw and deep the nurses were shocked by it. It was much worse than the original wound, but after three months of daily packing the wound has healed. No sinus, just a neatly healed bottom. Nag the surgeon and tell him you want it reopened, as deep as he can as something is stopping it healing. At one point we were advised it was better to live with the sinus.

Mr & Mrs C Lewis

Dear Editor

At the age of eighteen I was involved in a road accident, in 1958. I was horrified to find I would never walk normally again. Thanks to the encouragement and treatment at Stoke Mandeville Hospital, I adjusted myself to life in a wheelchair. I thank God daily for giving me the strength to go on.

I married a wonderful man in 1962, and by the time I was thirty we became proud parents of three sons, all born naturally. Becoming a paraplegic meant lifting myself on and off the toilet frequently, and my shoulders felt the pain. My doctor described how a colostomy could help solve the problem. After discussions with my family, a colostomy was fitted in February 2010. It is a wonderful feeling to be in control of this bodily function. On a recent hospital visit I was surprised when a senior nurse asked me to show her how it all works! It was a pleasure to take the role of a teacher!

Jill Smith

Dear Editor

I commend your article in the autumn edition "Hints and Tips for new Colostomates" and only wish I had such comprehensive practical advice in my induction to colostomy management eight years ago.

From my own experience, I would like to add a gloss if, I may, to emphasise the usefulness for the newcomer of those little sticky filter patches which come with each box of pouches. Not only do they perform the obvious functions of keeping water out of the pouch during showering or bathing and saving the embarrassment of escaping odours on social occasions, but, as your article rightly points out, they are an important means of helping to avoid pancaking and leakage by retaining a quantity of gas to assist the downward flow of output to the bottom of the bag. In my own case I have made it part of my routine to attach a patch to the filter whenever I put a bag on. This gives me the pleasure of knowing that I do not need to restrict my diet in any way in to avoid gas–forming foodstuff as I have the confidence of being able to retire to the

CONTINUED ON PAGE 22, COLUMN 1

Readers' writes

CONTINUED FROM PAGE 21, COLUMN 3

loo to lift the patch and gently squeeze the bag to expel any excess of accumulated gas, leaving just enough to prevent pancaking. The patches are sticky enough to be reattached several times during the day.

Michael J Ward

Dear Editor

Regarding BB's problem with wind, this has also been an issue for me – mainly noise, but occasionally smell. I have not tried the Hollister pouches, but I have tried several others, and have found the Coloplast pouches to have the best filters. I currently use the Sensura Mio. I also use drainable bags, but with the Coloplast pouches I do not have to vent them (I did with some other makes).

I don't know if it is an option for BB, but what made the biggest difference for me was irrigation. The amount of wind is considerably reduced, and I can now wear a support belt for my hernia. The belt also helps to muffle the noise when my stoma decides to let rip.

AM

Dear Editor

I answer to BB in the last issue, I too had wind problems and stomach ache following my colostomy. Changing foods didn't help, and in the end it turned out to be a milk problem. Changing from the commonly available A1 milk to A2 milk cured my problem

Look up "Lactose Intolerance" on the internet and this will give all the details. A2 milk is available from all the big supermarkets. Before changing your diet you should really talk to your GP.

J Morris

Dear Editor

Having just read a letter on page 34 of the recent *Tidings*, I can confirm that plastic surgery does work. I had exactly the same problem for nearly 4 years. My consultant eventually did refer me to the nearest plastic surgery team at Southmead Hospital, Bristol after countless different dressings were tried and also a visit from a specialist tissue viability nurse who recommended vacuum therapy (nothing worked). The consultant at Southmead, Mr Wilson, was shocked to know that I had been left in such a state for so long. The unhealed wound I had was 5cms deep and I was having to go to the GP surgery every other day to have it repacked. There it was hinted that constant repacking of the wound was hindering healing. Anyway it did take the plastic surgery team 2 attempts to finally close the wound (using pig skin!). That was 18 months ago and I've never had any problems since, apart from not being able to sit properly for a couple of months. I got the impression that this type of plastic surgery in that area is relatively new and that is why it took 2 operations to make it work. I cannot praise highly enough the care and support I had from Southmead Hospital. I hope this helps.

Maragaret Rees

Dear Editor

I love irrigating!

Thank you Sarah for your article on irrigation, you are right, everyone is different and use various techniques but at the end of the day we have a sense of empowerment.

I have irrigated for eight years, encouraged by my stoma nurse at the JR in Oxford (who I am eternally grateful to) and have found that it gives me a greater freedom and confidence, fair enough I have blowouts as we all experience but they are rare. I am on my 3rd stoma which is above the level of my umbilicus, so is quite visible so it does mean that I don't have to wear a pouch, just a small cap about 8cms wide which is hardly noticeable.

I irrigate every other day and it takes me about 15–20 minutes and I have done it in some weird places, a "junk" in the south China sea, a train in Vietnam where you could see the rails whizzing past through the hole in the floor and In Iceland (not the shop) where the water is really sulpherous and a neighbour would wave to me as he went passed the window!

Strangely I nearly always sneeze when irrigating although I'm on a load of antihistamines all year round but they don't seem to affect how long it lasts.

The only downside is that irrigation doesn't agree with the cat, who always thinks that it is a safe place to snuggle between my feet and never learns that it really isn't!

Mo Nisbet

Dear Editor

I have a urostomy and an ileostomy. (I joined the **Colostomy Association** soon after my surgery as I thought that the *Tidings* magazine looked interesting and that the association was doing something worthwhile).

I read with interest and a little concern Kathy's letter in the Autumn issue of *Tidings* with regard to using a night urine bag on a flight. I would be concerned about two aspects of doing this. Firstly from a practical point of view had she considered what would have happened if, whilst asleep there was an accident with the bag? e.g I have experienced the tube disconnecting, amongst other problems, whilst asleep, with messy consequences. This would have been a hundred times more difficult to deal with during a flight! A night flight would be worse, as cabin lights are dimmed. Or had she considered turbulence, causing the bag to pull away and possibly even drag her urostomy bag away from her body? How did she intend to deal with connecting/disconnecting the night bag? How would her husband dispose of the bag at the end of the flight, as it could be considered medical waste? Had she

Readers' writes

told the cabin crew of her plan, in case they saw a strange looking device with a tube and thought it could be a bomb?

There are alternatives. How about, if she felt that she needed a long sleep, setting an alarm on a watch, set to wake her up every couple of hours If you don't own an alarm watch they are pretty cheap to buy. Or perhaps she could have used a leg bag, which is more discrete than a blanket and easier to manage.

David Cable

Please Note: Before acting on suggestions from other ostomates you are advised to check with a doctor or stoma care nurse that this course of action is suitable for you.

For more information about the issues discussed in these letters i.e. travel, colostomy irrigation, colonoscopy etc. contact **Colostomy UK** 24–hour free helpline **0800 328 4257** or visit **www.ColostomyUK.org**

Moved by something you've read in this issue of *Tidings* magazine? Do you have an issue that needs addressing or an experience you'd like to share with our readers?

We want to hear from you

Colostomy UK regularly receives correspondence from supporters across the UK who would like to share their thoughts, experiences and personal tips.

All letters and e–mails are considered by the editorial team who decide which will be published in *Tidings* magazine.

If you'd like to send a letter to be considered for inclusion on the Readers' Writes page please send an e–mail to:

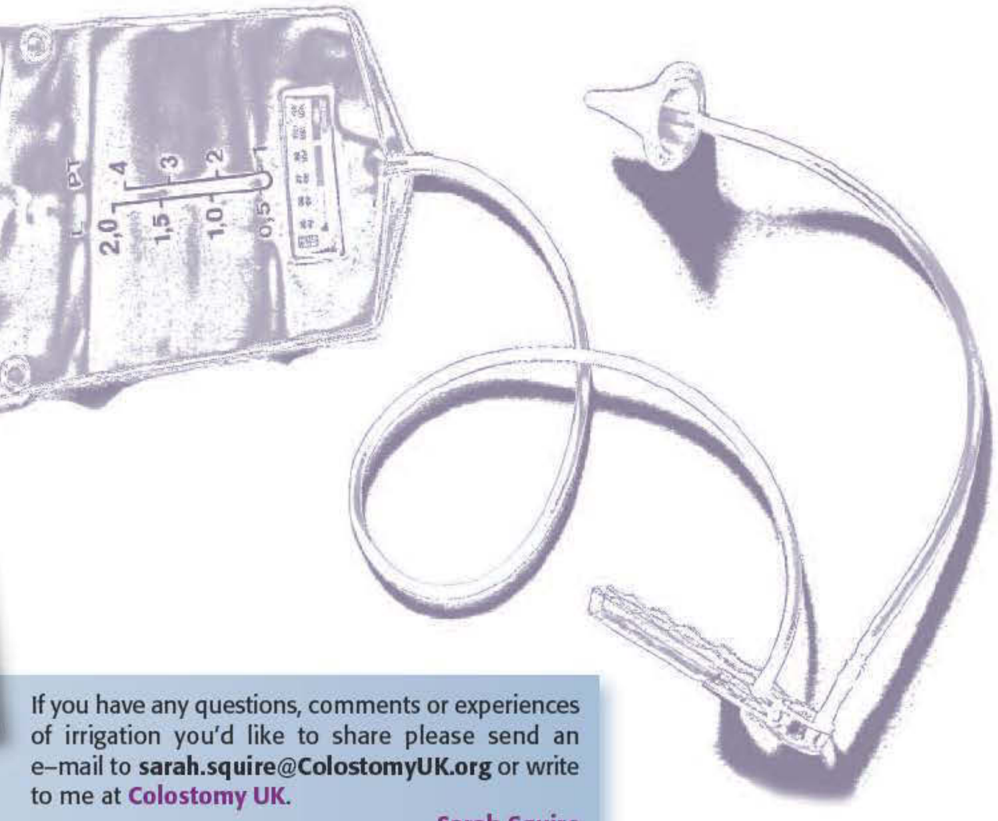
editor@ColostomyUK.org

or a letter to:

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

Please make sure you include your full name and address and telephone number so we can contact you. Additionally, please mention whether **Colostomy UK** has permission to publish your letter and whether you would like us to use your full name or just your first name. In the interests of confidentiality, if you do not give us permission to use your name we will publish only your initials.


NEW
Appeel.
Advance
NO STING
Appeel
No sting
Medical
Adhesive
Remover
Spray



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

Sarah Squire

Irrigation and You

Thank you so much for all the letters I've received from fellow irrigators. I love to hear your stories. This time we hear from two readers and their experiences of irrigation. Steve is a runner and irrigation helped him overcome worries over his stoma performing while he is out and about. Sonia is a master irrigator, having started almost 40 years ago! I'm sure can learn a thing or two from her years of experience.

Steve

Steve writes:

Well, if you are reading this the presumption is that we are all in a similar situation. After surgery the next hurdle is getting used to colostomy bags which come in all shapes and sizes. My stoma nurses have been exceptional as each problem that occurs, they manage to find a suitable solution.

Having been a club runner for 17 years I could not wait to get fit again and join the rest of my group on Club night exploring the footpaths in our area. To get fit after the operation I took very gentle walks at first only doing a few hundred metres then rapidly progressed to completing two and a half hour walks and I then started increasing the pace. Soon, after five months, I ventured out on a Tuesday night club run but what a

CONTINUED ON PAGE 26, COLUMN 1

CONTINUED FROM PAGE 25, COLUMN 3

disaster. After four miles my bag started activating, so much so that it filled and was forced off my body which was followed by a lonely and embarrassing run back to the club and a horrible drive home. The joys of a colostomy bag, never predictable!

What followed was an inspired suggestion from my stoma nurses, irrigation. It has transformed my life. The nurses helped me for the first three times, on the first occasion I had a little wobble due to a loss of blood pressure, apparently happens to some at first. It was quite amusing and has not happened since. The gravity irrigation system works very well but I have just been lent an electric pump system which makes the procedure so much easier.

The confidence it has given me to go for long runs without the worry of an incident is wonderful as after each irrigation there is no output for at least 30 hours and often longer. I have now completed a 10 mile road race and a five mile trail run but the ultimate achievement was the Stanage Struggle Fell Race where I achieved the same time as the previous year which proved I was back.

We are all of different physical abilities but with irrigation I feel all can get back to not only what you were doing before but also back to the same intensity. This may be walking to the shops or taking part in a sport but I am sure irrigation will improve most people's life.

Editor's note: As Steve described, some people may experience a drop in blood pressure the first time they irrigate and feel a little faint. This is due to a reaction of the vagus nerve following the introduction of water to the bowel. This is one of the reasons you must be trained to irrigate by a stoma nurse, but it shouldn't continue after the first one or two irrigation sessions. If you have any questions regarding the influence of the vagus nerve on irrigation please ask your stoma nurse.

Sonia

Sonia writes:

In May 1978 I had major surgery because the malignant tumour was awkwardly situated. The rectum had to be removed and a colostomy formed. From 1966 until 1985 I lived in the US so my surgery took place there. One very big difference was (and probably still is) that irrigation was taught within a few days of the surgery. The hospital did not want to send you home until you could irrigate. (This reminded me of not being able to leave the hospital after giving birth until you could feed the baby. My twins were born in the UK in 1962 and I was encouraged to breast feed them simultaneously – which I never managed. I went home with the babies and bottle fed them.)

In May my colostomy will be 40 years old (I will be 80 in less than a week's time) and, although occasionally I have irrigated twice in a day, I have irrigated more than 14,300 times. I still feel it is a worthwhile exercise, although I never look forward to 8:00pm and irrigating and often would very much like to put it off. However, I know I will feel better after irrigating and it is just one hour of discomfort for 23 hours of not being concerned about my system. I do not drink alcohol as I find that accelerates the gut and I eat carefully. I never look at a menu and think what would I like to eat but always think about what would sit well. Fortunately my husband likes nursery food [plain food] and although I like a greater variety of food, nursery food suits my digestive system well – boring as it can be.

Usually I feel quite unwell when irrigating. I sit on a stool in front of the loo and using an electric pump insert 1.5 litres of water through the stoma into the intestine. Quite quickly peristalsis starts and after about 40 minutes the bowel is empty enough for there to be 24 hours of no bowel activity. Unfortunately that 40 minutes is often most uncomfortable but I distract myself by watching mindless television. Once the bowel is no longer active I shower and then go to bed.

Editor's note: We would recommend anyone experiencing pain during irrigation should contact their stoma nurse for advice.

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

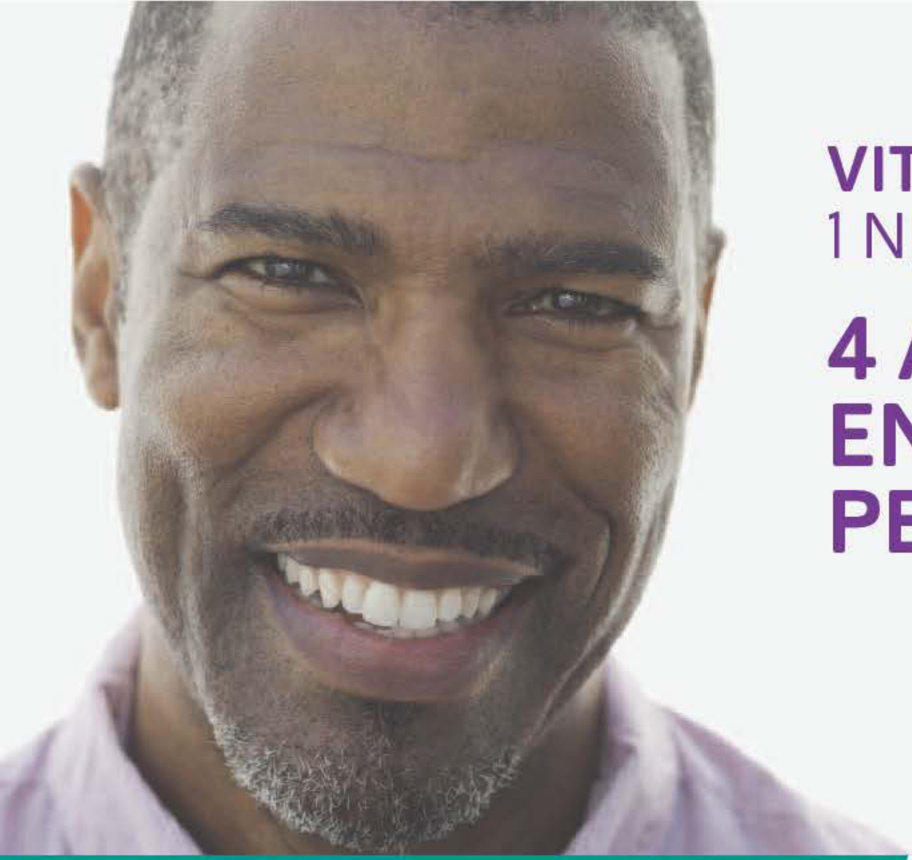
Many ostomates prefer this method of colostomy management as it gives them a sense of control. If you feel you would like to try irrigation you should first contact your stoma nurse to see if you are a suitable candidate. If you get the go ahead they will then arrange a time to teach you. For more information see the **Colostomy UK** website or purchase the *Irrigation and you* DVD using the form on the bottom of page 44.

Please remember these experiences are personal to Steve and Sonia. Before acting on suggestions from other ostomates you are advised to check with your stoma care nurse that this course of action is suitable for you.

Red Rose

Visible reminder
Constant companion
Noble grandeur
Alien lander
Ad hoc actions
Random noises
Mixed reactions
Dawn chorus
Life or death
Rescued body
Face the truth
Red rose study
Waste away
Discreet package
Disposal play
Off load and sack it
Face the change
Embrace and courage
No matter how strange
Grow and flourish

Karen Clegg



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59% Reduced Skin Irritation

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Moisturising

Faster Healing

Kinder to Skin

Anti-Inflammatory

The new Platinum with Vitamin E Range

Faster Healing

"Had an area at the edge of the adhesive that finally healed"

Anti-Inflammatory

"Felt more confident and comfortable and didn't irritate skin when playing rugby"

Kinder to Skin

"My skin was red and some broken when I used the Vitamin E pouch the skin began to return to normal"

Moisturising

"My skin felt nourished, soft and less irritated"

pelican platinum with Vitamin E

Available in closed, drainable, high output, convex and urostomy.

Mary* - Feeling comfortable for the first time in 35 years!

pelican platinum with Vitamin E

After 45 years of having a stoma and 35 years of discomfort, Platinum with Vitamin E has really made a difference to 95-year-old Mary. Despite enjoying a full and active life, Mary always had a feeling of soreness and thought it was all part of having a stoma. She had just put up with the problem which included her skin being dry, crusty and uncomfortable. That was until she was introduced to Platinum with Vitamin E.

Our Pelican nurses realised that the product Mary had been using was the source of the problem, and that changing to Platinum with Vitamin E would improve her comfort. Within a week Mary's skin had started to improve and within 4 weeks it had completely healed and no longer experienced any discomfort. After using Platinum with Vitamin E Mary said 'my skin has improved after over 35 years of soreness'.

*Case study name changed to protect privacy

> "My skin has improved after over 35 years of soreness"

Before

After

Sample now

For complimentary samples, call us now on 0800 318 282

Your complimentary sample

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Name ....

Address ....

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Postcode ....

Mobile ....

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Please detach and send to:

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Pelican Healthcare Ltd, Greypoint, Cardiff
Business Park, Parc Ty Glas, Cardiff, CF14 5WF

Please select a pouch type you would like to sample:

Closed ☐
Drainable ☐
Urostomy ☐

Flat ☐
Convex* ☐
Stoma Size (mm) ....

*** Please contact your stoma nurse before ordering convex**

The information supplied on this form will be retained by Eakin Healthcare Group on a database. The data will not be disclosed to any external sources. Please indicate here if you do not wish to hear of further products and services available from Eakin Healthcare. ☐ TO118

pelicanhealthcare.co.uk pelicanhealthcareltd @PelicanHealth

Update on stoma care products and services

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

Coloplast new product

Sign up to Coloplast® Care today

Coloplast Care is an online support programme for people with a stoma. Whether you are a new ostomate or have had one for years – we offer a helping hand by providing advice on how to solve common issues with your stoma, tips on your routine and practical advice on lifestyle including diet, travel and exercise. All of this is available to you on our Coloplast Care website and we will send you news, advice and ongoing support by email.

See our main advert on the inside front cover.

Coloplast® Care

Find out more by completing the coupon at the front of this issue or sign up today at **www.coloplast.co.uk/ColostomyUK**

OakMed – GoldCare online

It's now even easier to register for GoldCare online at **www.goldcare.healthcare** or by calling Freephone **0800 592 786**.

We'll then bring prescription stoma products straight to your door. Brand neutral, we supply any product from any manufacturer, whatever your age, whatever your needs and wherever you are in the UK.

See our main advert on page 40.

pelican platinum with **Vitamin E**

We have made an exciting change to our range of Platinum pouches that not only looks after your general stoma care, but also the healthy skin surrounding it. The hydro colloid on our new Platinum with Vitamin E range of pouches contains one new ingredient which gives you four areas of enhanced performance to promote moisturising, faster healing, kindness to skin and anti-inflammatory effects.

See our main advert on the centre spread.

How you can make a difference

You can help make a difference to thousands of people across the world who cannot afford stoma supplies by either donating supplies or making a financial donation. Please send supplies you genuinely cannot use to **Stoma Aid** at the following address:

Stoma Aid
c/o Stone Logistics/PRS Limited
Lorne Mill
Lorne Street
Bolton
BL4 7LZ

We cannot accept donations at our Reading office. Please do not be tempted to send or drop them off at the Reading address, as unfortunately we will have to refuse to take them.

Stoma Aid will accept all types of stoma appliances, including:

- Closed bags
- One piece bags
- Drainage bags
- Two piece bags (must include matching baseplate/flange)
- Drainable bags
- Urostomy bags

We are currently ONLY accepting donations of bags (within date) and cannot accept any other additional products such as wipes, cream, seals, aerosols and pastes etc at this time.

The cost of sending unneeded supplies to Stoma Aid can be reduced by using Hermes which has over 4,500 collection points across the UK. Prices start from as little as **£2.70** per parcel and more details can be found about the locations of their Parcel Shops on their website below (or by telephoning the **Colostomy UK** office with your postcode):
https://www.myhermes.co.uk/parcelshop-finder.html

Remember, help the NHS save vital funds – please do not over order supplies or over–stock items. Only send items ordered from the NHS in good faith that you now find that, for whatever reason, you cannot use.

Haven't got any supplies to donate but would still like to make a difference? Why not make a financial donation to Stoma Aid? Please make all cheques payable to Stoma Aid and send them to: **Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA**

Abi's story

As I write this, I'm approaching 15 months since my life changing surgery, being given a permanent end colostomy due to stage 2 rectal cancer. The surgery in August 2016 was a huge success but the recovery process has been an adjustment and quite a journey, with ups and down as you'd expect. However it's most definitely been UP most of the time! I am amazed how far I have come these past few months and if what I can share might encourage or help some of you, that will be wonderful.

I've always approached life with a positive attitude and with a smile on my face. This has been even more important these past few months as I emerge stronger and get my health back on track. Fitness has always been an extremely important part of my life – with 9–11 sessions a week at the gym the norm – yes I know that sounds like a lot! Bear in mind, this was a mix of cardio (treadmill, stair master, cross trainer etc) plus yoga/pilates and weight training. Going in for surgery I knew there would be a long rest period ahead of me. I made sure I took it careful and I didn't return to the gym for five months – instead just ensuring I spent time outdoors walking – and this was enough to maintain a reasonable level of fitness. I was still visiting the nurses at the surgery up until mid–February for my dressing (yes I have a barbie butt too!). I would encourage others not to push themselves too soon – listen to your surgeons and clinical team – there is no rush. Rest is so important, as is listening to your body.

During my recovery I have, of course, found that sometimes I have done too much (we know how easy that is!); and then paid the price with a couple of rough days. I run my own recruitment business so I feel the pressure to keep working, but I love what I do and find the activity gives me real focus. At times like these I remember to 'be kind to myself' and ensure I am getting more rest and keeping a watch on how much I schedule in my diary. Even now I simply can't handle two–three full on days in a row. As long as you are aware of your limits you can work around it.

There are a number of reasons why I think I am doing so well. I would recommend others consider:

- Regular sessions at the gym (once my body was ready) and eased my way back slowly but surely, building up strength, doing the Core 4 and keeping a diary of my progress – I do believe consistent exercise is good for us, helps our energy levels and quality of sleep but it's vital you adapt and be careful with lifting.
- Eating a healthy and well balanced diet, mix of protein and good quality fats and carbs; allowing myself those all–important treats! Think of food as your fuel!
- Finding the right bags that I am comfortable with – I use midi or mini bags for comfort – get samples, discuss with your nurse or call the helpline – there are so many options.
- Getting plenty of rest and ensuring I get a daily nap to keep my energy levels – schedule in that rest!
- Drinking coffee and alcohol in moderation; opting for water and tea throughout the day.
- Being open about my experiences has personally helped me.
- Being trained to irrigate by my stoma nurses has made an enormous difference – I would encourage those of you who are given this option to try, to give it a go. It was a commitment to get into a routine but definitely well worth it.
- I attended the **Colostomy UK** Open Day in September and found this hugely valuable.
- It's so great to be returning to my normal way of life with just a few adjustments in place. Having a colostomy has not diminished my quality of life and I am forever grateful that it saved my life! ■

Important changes to the bowel cancer screening programme

Reproduced with kind permission from NHS Health Scotland

Deborah Alsina MBE, Chief Executive of Bowel Cancer UK

Over 16,000 people die from bowel cancer each year in the UK – that's one person every 30 minutes. Yet bowel cancer is both treatable and curable if diagnosed early. In fact nearly everyone diagnosed at the earliest stage will survive, compared to less than one in 10 of those diagnosed at the latest stage.

We know the best way to achieve an early diagnosis for bowel cancer is through screening. The Bowel Cancer Screening Programme is aimed at those aged 60–74 (50 in Scotland). Eligible participants are sent a home testing kit in the post every two years. The test looks for the presence of blood in poo that can't normally be seen and doesn't show up on your toilet paper or toilet pan, which could indicate that there is a polyp (non–cancerous growth) or cancer in your bowel. The aim of the programme is to prevent bowel cancer and detect it early. One year survival figures for screening are 97%, compared to just 49% for those diagnosed as an emergency.

That's why we were pleased when in 2016 the UK National Screening Committee (UKNSC) recommended the introduction of the more accurate faecal immunochemical test (FIT) to replace the current guaiac faecal occult blood test (gFOBT) in the Bowel Cancer Screening Programme.

Over the years we have proactively engaged with the Bowel Cancer Screening Programme to campaign for this change. For example in 2015 we worked with the Independent Cancer Taskforce in England to ensure the adoption of FIT was included as a recommendation in the England Cancer Strategy, and we made a strong case for change in our response to the UKNSC consultation on whether the Programme should adopt FIT. Since then Scotland have changed the screening test used in the programme to FIT in November 2017, and England and Wales have agreed to do the same in 2018, but the situation in Northern Ireland remains unresolved due to the political situation. The charity is now an active member of the FIT Implementation Groups in all three of these nations.

What is FIT?

FIT works in a similar way to the current screening test by detecting tiny amounts of blood in poo that could indicate cancer or polyps, growths that can develop into cancer. However FIT measures blood in a different way from that used by gFOBT. FIT measures the level of blood in the poo sample whereas gFOBT only indicates the presence of blood. It also specifically measures human blood, which means it's not influenced by other blood in the diet. Because of this, it is more accurate.

FIT is now used around the world including in Italy, The Netherlands, France, Ireland, New Zealand, Australia, Spain, Slovenia, Malta, Japan, parts of Canada, and Southeast Asia.

Benefits of FIT vs gFOBT

The pilot studies conducted in England and Scotland found that FIT has many practical and clinical advantages over gFOBT including picking up more cancers and improving uptake.

Increased disease detection: The English pilot found that FIT picks up twice as many cancers and four times as many advanced adenomas (tumours). This is important because the more cancers we can pick up early, the more lives we can save. We know that cancers picked up through screening are more likely to be early stage cancers. The earlier bowel cancer is detected, the easier it is to treat and the greater chance of survival.

Higher uptake rates: FIT has been shown to increase the number of people participating in the bowel cancer screening programme, particularly for previous non–responders and first–timers, as well as hard to reach groups, such as ethnically diverse and deprived groups. It's anticipated that uptake will increase by around 10% and double in people who previously haven't responded. Currently only around half of those invited take part in the Bowel Cancer Screening Programme, meaning opportunities to detect cancer early are being lost.

Realising the benefits of FIT

If the full benefits of FIT are to be achieved then it is essential the test is brought in at a more sensitive level – meaning more people will receive a positive result and be referred for a colonoscopy. However a highly sensitive FIT will have significant impact on colonoscopy services, particularly as many endoscopy units are currently struggling to cope with an increasing demand for the service. Without additional investment in colonoscopy services the opportunity to detect more bowel cancers early and save lives will be lost and people will continue to die needlessly.

There needs to be a clear, timetabled and transparent programme of action to increase capacity at screening centres to ensure that sensitivity level can be increased over time.

Increasing demand

Demand for endoscopy tests has been increasing dramatically over the last few years – a trend that is set to continue. In fact, reports estimate that nearly a million more endoscopies in England alone will be needed year on year to meet this increasing demand. This is due to a number of factors, such as an ageing population, increase in symptom awareness and roll out of new screening programmes.

But despite the increasing demand for services, this hasn't been matched with investment to increase capacity to meet this.

Capacity for high risk groups

Lack of capacity is also impacting people who are at high risk of bowel cancer, such as those with certain genetic conditions like Lynch syndrome, which can increase risk of bowel cancer by up to 80%. People with Lynch syndrome should be placed in a surveillance programme to receive regular colonoscopy every 18 months to two years to help reduce their risk of bowel cancer. However those at high risk are often made to wait unacceptable lengths of time before being seen. Our research found that 49% of respondents to our survey on Lynch syndrome had experienced delays to their planned colonoscopy appointment, with 78% of these waiting more than six weeks beyond their planned procedure date. That's why we launched a petition calling for urgent improvements to the diagnosis and management of people with Lynch syndrome.

The case for investment is clear

Given the wide ranging impact that increasing demand and a lack of capacity is having on ability to provide services for bowel cancer, the case for urgent investment is clear. Investing in services that can diagnose bowel cancer is critical to ensuring units have sufficient workforce and infrastructure to carry out endoscopy and that all units are working as efficiently as possible. We need to do more than just papering over the cracks. We need to ensure diagnostic services for bowel cancer are fit for the challenges of the 21st century.

We've been raising this issue with key decision–makers for many years, published two reports highlighting the challenges and solutions and launched the right test, right time campaign. As part of this campaign we've been calling for a national endoscopy strategy and a training programme as a solution to the mounting pressure on endoscopy units. We hope to work with Government, the NHS and clinicians to ensure a sustainable endoscopy service that has the capacity to meet future demand.

Useful information

England will be rolling out FIT in 2018 and Wales in 2019. Northern Ireland is still yet to approve the new test. No matter which bowel screening test you receive in the post, completing and returning it could save your life.

Find out more about screening at **bowelcanceruk.org.uk/screening**

For more information call the bowel screening helpline for your country:

England: **0800 707 6060**
Scotland: **0800 0121 833**
Wales: **0800 294 3370**
Northern Ireland: **0800 015 2514**

What else is Bowel Cancer UK doing?

Last year, we launched our five year research strategy 'Unlocking the Key to the Cures'. Following extensive consultation with leading research experts, we've chosen four priority areas of focus for the next five years. One of them is 'to improve the prevention, early detection and treatment of bowel cancer.' We are determined to prevent as many bowel cancers as possible, diagnose earlier and improve treatment and care for all patients. We will specifically focus on:

1. Identifying ways of preventing bowel cancer.
2. Improving bowel cancer screening.
3. Understanding and identifying people at high risk of bowel cancer.
4. Understanding bowel cancer in the under 50s.
5. Ensuring best treatment and care for bowel cancer patients.

You can read more about our research strategy on Bowel Cancer UK's website

Another key part of our work is educating patients, the public and healthcare professionals about bowel cancer, in particular the importance of early diagnosis and screening. One of the ways we do this is through our health promotion volunteer programme, which has been recognised by the Royal Society of Public Health. Up and down the UK, hundreds of volunteers give talks to their local community about bowel cancer, raising awareness of the screening programme, how they can reduce their risk and the symptoms of the disease. Our expert team also runs study days and bespoke training events for public health and healthcare professionals.

How you can get involved

We are determined to save lives from bowel cancer but we can't do it without people like you.

- Sign up to our monthly e–newsletter.
- Share your story to help raise awareness and let others know they're not alone.
- Become a campaign supporter and take action to stop bowel cancer.
- Volunteer for us.
- Book a talk for your workplace or community group.

bowelcanceruk.org.uk

Bowel cancer screening can save lives.

At the moment in some areas of the UK only a third of those who receive a test complete it.

Bowel cancer is treatable and curable especially if diagnosed early. Nearly everyone diagnosed at the earliest stage will survive bowel cancer.

Taking part in screening is the best way to get diagnosed early.

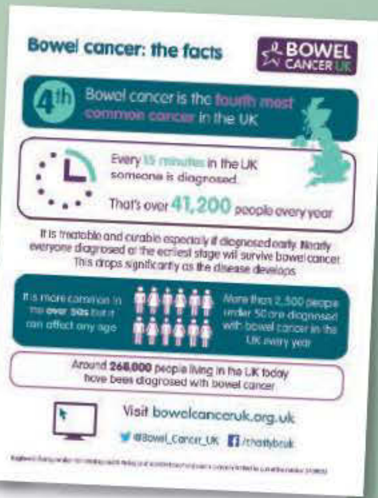
If you are over 60 (or over 50 in Scotland), take the test when you receive it in the post

Take the test!

If you are younger, tell the people over 60 (or over 50 in Scotland) in your life, to take the test.

Visit bowelcanceruk.org.uk/screening

@Bowel_Cancer_UK /charitybcuk



Bowel cancer: the facts

Bowel cancer is the fourth most common cancer in the UK

Every 15 minutes in the UK someone is diagnosed.

That's over 41,200 people every year

It is treatable and curable especially if diagnosed early. Nearly everyone diagnosed at the earliest stage will survive bowel cancer. This drops significantly as the disease develops.

It is more common in the over 50s but it can affect any age

More than 2,500 people under 50 are diagnosed with bowel cancer in the UK every year

Around 268,000 people living in the UK today have been diagnosed with bowel cancer

Visit bowelcanceruk.org.uk

@Bowel_Cancer_UK /charitybcuk

We would like to thank Deborah Alsina of Bowel Cancer UK for submitting this informative article. Obviously, regular screening for bowel cancer is vital for ostomates too, so we contacted Professor Richard Logan (Director of the Eastern Hub of the Bowel Cancer Screening Programme) to ask whether the FIT test was suitable for people with stomas. We encourage you to read his response (below) as it contains important information:

'…for people with a stoma anything that could produce a small amount of bleeding from the edges of the stoma or from the lining of the bowel just within the stoma will quite likely result in the FIT showing blood. As this would be fresh blood as opposed to blood that had arisen from further round the bowel it is quite likely to give a high FIT result. I would imagine that managing the stoma with irrigation could produce some bleeding. However we have no evidence yet as to what would happen in practice when a FIT is used. We do get reports on our Helpline from ostomates who say that they often see small amounts of bleeding from around the stoma.

My advice therefore to ostomates sent a screening test would be to firstly check whether it is appropriate for them to do the test. I don't know what proportion of ostomates have had their stoma created for cancer. For those who have had their stoma for cancer they should be being followed up by a surgical unit or hospital where it was done or where they now live. The current recommended follow up is a colonoscopy at 5 years and another at 10 years as well as at 1 year for those people who did not have a colonoscopy for the diagnosis of their cancer. If an ostomate has had a colonoscopy at these intervals and nothing serious found there is little to be gained by them completing a screening test whether it is the guaiac FOB test or the FIT when it is introduced.

For those who have had their stoma created for other conditions or who had a stoma created for cancer before the age of 50 then they should collect the samples much in the way that the excellent article you sent proposes. (Prof Logan is referring to our article on bowel cancer screening that appeared in the Spring 2013 edition of *Tidings*. You can download this edition free from our website. Alternatively please call the helpline and we will send you a copy of the article.)

Win up to £25,000 with Unity

50p
From every £1 goes to Colostomy UK

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

How it works

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

How to join – three easy steps

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

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

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

If you have any queries please call our hotline on
0370 050 9240

Results & Rules can be checked by visiting
www.unitylottery.co.uk

Or by phoning the Unity winners hotline
0370 055 2291

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

Prizes	**£25,000** 6 digits	**£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)

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:

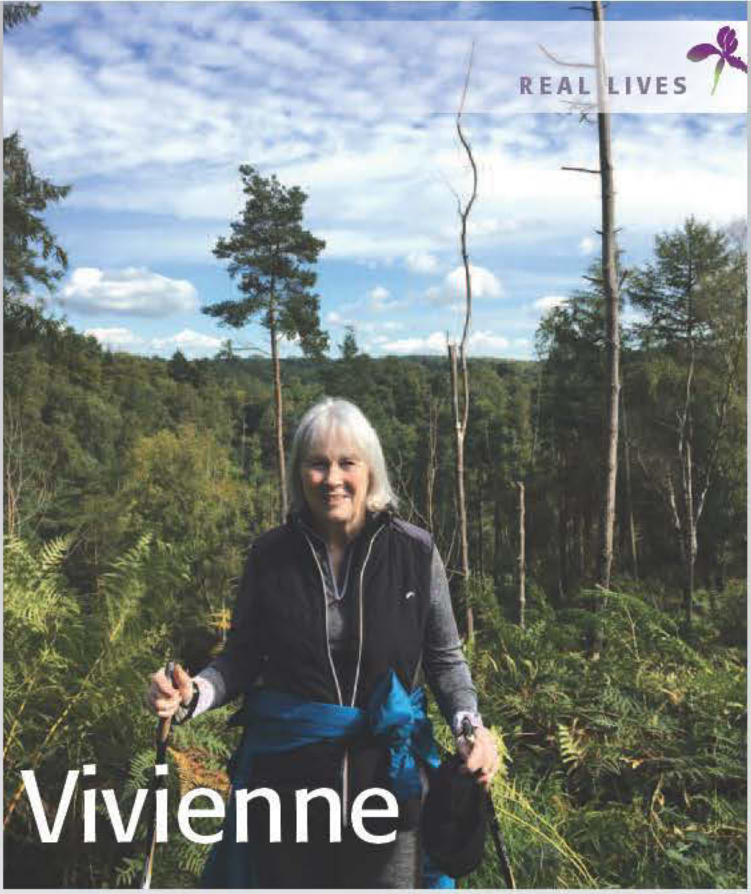
The Unity Lottery
Furness Gate
Peter Green Way
Furness Business Park
BARROW-IN-FURNESS
LA14 2PE

For office use only:

T46

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



Wow, a year this week, and yes I am celebrating, its been a year of change, certainly a year of challenge.

Sigmoid versus Vivienne

The early black October clouds in 2016 have risen, and I am still here, stronger and wiser physically and mentally. My journey has just begun.

Sigmoid has left, Vivienne was born

The diverticular stopped me in my tracks, slowed me down, with regular nasty prolonged attacks, living an active life around it, seeking out alternatives, diets, exercise, and spending hours sitting in doctors surgery waiting for some form of relief, some magic cure.

My geography on the best placed toilets throughout the UK and abroad deserved the acknowledgement of a masters degree.

The perforation floored me followed swiftly by the invasion of peritonitis, Even in the emergency of it all, I still thought been here done this before, all will calm down, a couple of pain killers and then back home.

No not tonight. Only moments to say goodbye, and then a nothingness my lost days. Parts of this experience I fail to recall, some haunted me, for weeks after coming home, flash backs that received the desired effect on me, allowing myself to become a crumbling wreck, and the greatest fear of ever having to go back into hospital again.

Like magic within the comfort of home family and friends and my own self again, my journey begins, and from the start I planned what I wanted to do, so my tick list began.

It's important for me to have new goals, see places and participate in physical challenges that will stretch me.

This year has been life changing but for the better, I value life, and have learned to respect myself, by accepting that each day is a new day, and if Vivienne decides to hold me hostage for a day or two, life itself for me is one hundred times better than before my stoma.

I have laughed with others and laughed at myself, new friendships have been formed, and the rush to the nearest toilet has been abandoned to a more relaxed chilled me.

I hit 70 in February 2017 four months post op, yes I celebrated, nothing has stopped me, nothing is going to stop me.

I have sailed away on a UK Ireland cruise, and did a flight to Spain, thats another story. Managed a helicopter flight, and travelled on the train to Newcastle–upon–Tyne, might not sound like much a train journey, but its another tick.

Exercise plan I changed to suit my needs, I was active prior to my stoma, but some things needed adjustment.

My Freedom Passport sounds apt for the changes we encounter with a stoma but it is also for me.

My freedom Passport to White Peak Nordic Walking

I joined about five weeks ago, and this week celebrated finishing my course and receiving my passport. (Certificate).

Never underestimate the power of the poles, and what this style of walking can do for your well being, It has helped me regain not only my confidence also my muscular strength, and my posture which both seemed to have collapsed pretty quickly post op. It teaches you to balance, so preventing unwanted falls, and flexibility which again I noticed in myself seemed to become stiff and painful due to me being afraid to move in the early days of post op.

There are so many walks to suit individual needs, I never felt out of my depth or out of place in our small group.

I was the oldest, and yes at first I did get puffed out going up the inclines, that's good at least my heart was still pumping away even if at times I felt it was about to pop out of my mouth, but I took my time I wasn't rushed or left behind, and the poles propelled me, without them I certainly wouldn't have travelled so far. In six weeks I feel healthier in mind and body, and my breathlessness has managed to lose itself on route.

With winter fast approaching it's time to prepare for the long dark nights and short days, and allow ourselves a place to be and places to go not far away and within the reach of us all.

Maggie Wright

Get your Colostomy UK 2018 Calendar

Last chance…so prepare for your virtual holiday!

Ever sat there on a cold miserable day and wished you were somewhere else? If so, then our 2018 Calendar is just the ticket. Spiral bound and measuring 210mm x 420mm, each month opens to reveal a stunning photograph which, with a little imagination, will see you jetting off to faraway places. We have everything covered, from cityscapes to sunsets in tobacco coloured skies. There is also plenty of space to record appointments and even, perhaps, the date of your 'real' holiday.

Our calendar competition received a total of 96 entries and, just like 2016, the standard was so high that it caused our judging panel a few headaches. Every single photograph was taken by one of our supporters. Mr Kevin Young was the eventual winner with his photograph of a sunset near Stromness, Orkney, Scotland. Second and third place went to Mr Trevor Andrews and Mrs Phyllis Oliver respectively, with photographs of Castillo de Casares, Málaga, Spain and Yardenit Baptismal Site along River Jordon, Galilee, Israel. They say that a picture is worth a thousand words. We couldn't agree more. Those that make up our new calendar are more than just visually stunning. They are also tangible evidence of ostomates living full and active lives.

The calendar costs **£9.50** including postage and packing. All proceeds will help support the various services we offer including our 24/7 Helpline, our extensive range of free booklets and, of course, *Tidings*. So don't delay ordering. What's more, every calendar comes in its own white presentation envelope, making it an ideal gift.

Calendars can be ordered using the form below or via our online shop.

Shipping now

Please send me [Quantity ____] **Colostomy UK 2018 calendar**/s at the cost of **£9.50 each** (price inclusive of VAT & p+p). Please allow 28 days for delivery.

I enclose a cheque for [£ ____] made payable to: **CA Commercial Ltd.**

Title:

Name:

Address:

Postcode:

Tel:

Email:

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

Active Ostomates

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

'Active Ostomates supports you to get fit and healthy with a range of programmes. Some are delivered via 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 help everyone to get more active.'

Aiming High

Milton Keynes and Bracknell were the venues for a series of Archery taster sessions that took place over the summer with the support of The Milton Keynes Stoma Association, The East Berkshire Ostomy club, Crowthorne Archers club and Silver Arrow Archery.

Attendees were able to do their best Robin Hood impressions while under the guidance of expert coaches from both clubs.

Chair Yoga

Ostomates in Milton Keynes, Chester, Stevenage, Sheppey, Swanley, Wycombe, and Ealing have benefited from **Colostomy UK** chair yoga taster sessions recently. Some of the health benefits of yoga include relaxation through deep breathing, which when combined with physical movements can rid the body of tension and stimulate the flow of blood, and therefore oxygen, to different parts of the body. Yoga can stimulate the nervous system and make muscles and joints more flexible.

Our chair yoga sessions are run in partnership with stoma support groups throughout the UK.

If you are a member/organiser of a support group and would like to join our Active ostomates project please contact **Giovanni.Cinque@ColostomyUK.org** or on **0118 939 1537**.

Walk your way to fitness with Active 10

Colostomy UK is supporting the ACTIVE 10 initiative from the NHS.

A brisk 10 minute walk every day can make a difference to your health. Each 10 minute burst of exercise is known as an "Active 10".

Brisk walking is simply walking faster than usual, at a pace that gets your heart pumping. Start with a 10 minute brisk walk a day and then see if you can gradually build up to more.

It's the easy way to improve your health and wellbeing. No gym memberships, no Lycra. Just 10 minutes and you!

For more information including how to download the free Active 10 app visit: **www.nhs.uk/oneyou/active10/**

Do you play Rugby League or Football?

Colostomy UK are looking for ostomates who would like to, or already play, Rugby League and are aged 35 and over, and Football and are aged 50 or over, for an exciting new project. If this sounds like you please get in touch with Giovanni Cinque at **Giovanni.Cinque@ColostomyUK.org** or on **0118 939 1537**.

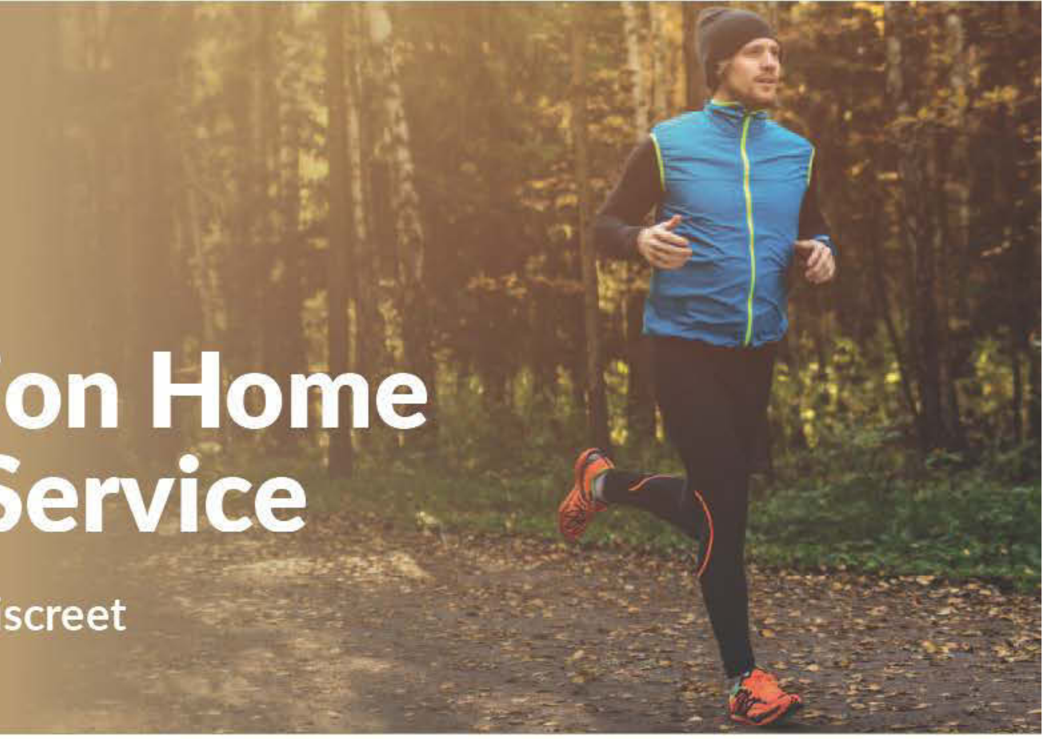
Sport and fitness after stoma surgery booklet

We are delighted to announce that our booklet: *Active Ostomates: Sport and Fitness after stoma surgery* was 'highly commended' at the recent British Medical Association Patient Information Awards.

The judging panel commented that it was: "an excellent resource which should do well". This prestigious event, which is held each year, aims to support and encourage patient–centred care through the production and dissemination of accessible, well-designed and clinically balanced information. Trustee Ian Jackson and Dr Richard Biddle, our writer and researcher, attended on behalf of **Colostomy UK** (pictured below).

The booklet includes advice on managing your stoma, hernia prevention, gives examples of a number of core exercises to try at home, and covers how to take up a number of sports and activities including Walking, both codes of Rugby, Running, Cycling, Swimming, and yoga.

For a free copy just call us on **0118 939 1537** or email: **info@colostomyuk.org**



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The GoldCare promise is designed to reassure you of our prompt & impartial service. Our GoldCare Nurses are also on hand if you need help or advice on stoma, bladder or bowel care.

PLUS our carefully selected range of complimentary items is designed to help you after surgery and includes luxury toilet bags and radar keys.

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Help Stoma Aid with a Bag for Life

Order our NEW Stoma Aid 'bag for life' and help give ostomates worldwide a 'bag for life'.

Our new Stoma Aid 'Bags for Life' come in two styles, a cotton Tote Bag at only £2.49 + £2.50 P&P (measuring 38cm x 43cm) and a larger more robust Jute Bag for £4.99 + £2.50 P&P (47cm x 32cm).

An ideal present, both bags make a statement when you are out shopping! The caricature was designed by a professional cartoonist whose work has appeared in a number of famous comics.

All profits from sales will go to Stoma Aid. So help us to continue our support of thousands of ostomates in need worldwide by buying one (or more) of our Bags for Life.

Order Form

To order your **Bag for Life** simply fill in your details below and return it with a cheque made payable to **Colostomy UK** and send to:

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

Alternatively, you can order your **Bag for Life** from our online shop at **www.ColostomyUK.org**

Insert quantity of bags required in each box:

☐ Cotton Bag £2.49 each plus £2.50 P&P ☐ Jute Bag £4.99 each plus £2.50 P&P

Title:

Name:

Address:

Postcode

Tel:

Email:

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

Junior Ostomy Support Helpline

This helpline is available for parents or carers of children with bowel or bladder issues.

Our specially selected team of dedicated parent volunteers provide much needed emotional support when it is required.

Helpline:

0800 328 4257

Supporting and empowering you

Colostomy UK

Looking for online support?

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

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

We look forward to welcoming you.

www.ColostomyUK.org

Freephone helpline:

0800 328 4257

24/7

Julie Rust answers your questions about prolapsed stomas

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

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

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

A *Tidings* reader wrote in following a letter in the spring 2017 issue. Prolapse questions come up regularly so Julie has explained what they are and how they can be treated.

JR wrote: *I hope your reader with the prolapsed ileostomy has had it fixed. My colostomy prolapsed filling the bag the day after it was fashioned. Back to theatre to remove some of the bowel. It prolapsed again during radiotherapy treatment which had to be cut short. Things were sorted a few months later when I had the APeR. I was distressed by a third prolapse about a year later and this lead to a visit to the stoma nurse and a couple of days in hospital. I have not been prolapse free for seven years.*

What is a prolapse?

A prolapse of the stoma is where the bowel which forms the stoma telescopes out through itself and increases the length of bowel visible externally. This can be quite distressing for patients and quite difficult to manage with regards to pouch adhesion if the prolapse is very long. Any sort of stoma can prolapse, be it end or loop, colostomy or ileostomy, although a loop is often deemed more susceptible to prolapse. The prolapse may be positional and you may notice it is more evident when you are standing but that it spontaneously reduces when you lie flat. This may be a more appropriate time to apply the stoma pouch as it may make the process easier.

What causes a prolapse?

There are many factors which can contribute to prolapse including:

- Obesity.
- Pregnancy.
- Surgical technique including the opening in the abdominal wall being too large.
- Lax abdominal muscles.
- Increase in abdominal pressure, often due to excessive coughing.

Can we prevent a prolapse?

Being aware of the contributing factors may help us to identify those patients at risk and therefore give advice and support to try to prevent prolapse occurring. Advice with regards to weight loss and exercise to increase the strength of the abdominal muscles may help as well as advising patients to support the abdomen when coughing, especially in the early days. Good surgical technique is also very important.

When is it important to consult a stoma care nurse and how may a prolapse be treated?

If a prolapse is large enough to prevent pouch adhesion and you are having leaks from the stoma appliance or the stoma itself is becoming ulcerated then you should seek a review with the Stoma Care Team. They will not be able to repair the prolapse, this can only be done by undergoing further surgery but they will be

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able to advise with regards to appropriate appliances to use and also with regards to how to apply the appliance over a large prolapse and may also advise the use of something such as Orabase Paste to treat any surface ulcerations of the bowel. If the prolapse does not reduce and becomes swollen the blood supply may be compromised and then the stoma may change to a darker colour and may be cool to touch. The function may also change with signs of obstruction including abdominal pain and swelling, sickness and possibly vomiting. This is an emergency situation and you should contact your GP and possibly referral to the hospital for urgent review. If you are unable to contact the GP or stoma care nurse for advice the Out of Hours GP needs to be contacted as soon as possible.

In conclusion a prolapsed stoma will require some changes to your daily routine, including monitoring the colour, output and temperature of the stoma as well as a possible change in appliance to one with a larger flange and cutting area. You may also have to empty the pouch more frequently as the extra length of the bowel in the pouch will reduce the capacity and therefore it will fill more often. With a prolapsed stoma you may need to alter your lifestyle slightly to accommodate this such as reducing physical activities. Prolapse belts are also available but should only be used following review by your stoma care nurse due to the potential of trauma to the stomal prolapse. Finally if the prolapse is causing significant problems or is ulcerated or non reducible a referral to a surgeon may be required to see if refashioning is possible. ■

A prolapse

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

E–mail:
editor@ColostomyUK.org

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

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

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

Colostomy Irrigation and You DVD

Order Form Colostomy Irrigation and You (Patients)

Colostomy Irrigation and You is an educational DVD aimed at patients, it has been produced by the **Colostomy UK** to raise awareness about ***colostomy Irrigation* as a method of bowel management.**
Note: Not all colostomates have the potential to irrigate. It is therefore essential in the first instance to consult your Surgeon/Stoma Care Nurse as they will advise as to your suitability.

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

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

Fundraising Focus

Our fundraising promise

Colostomy UK is registered with the Fundraising Regulator. We are committed to respectful, open, honest and accountable fundraising. The Fundraising Regulator sets and maintains the standards for charitable fundraising. For further information, including our complaints procedure and a link to the Regulators website you can visit **www.colostomyuk.org/get-involved/our-promise-to-you/**

As we are dedicated to delivering a high standard of service to everyone who engages with us, we are keen to hear should we ever fall short. You can provide feedback by calling us on **0118 939 1537**, by e–mailing us on **info@ColostomyUK.org**, or by writing to us at:

Colostomy UK, Enterprise House, 2nd Floor, 95 London Street, Reading, Berkshire, RG1 4QA

We will acknowledge and provide an initial response to your feedback within 10 working days of receiving it.

2017 Raffle

Thanks to everyone who purchased a ticket for our annual raffle.

The draw was made on Friday 29 December 2017 and the winners will be notified shortly.

A big thank you goes out to everyone who purchased tickets. Look out for details of our prize winners in the next issue.

An Evening of Comedy

On 3 November 2017 an evening of comedy, cartoonery, poetry and improvisation was held at The Duchess Theatre, Long Eaton, Derbyshire. Ian Macmillan, poet, journalist and broadcaster, began with amusing observations, stories and anecdotes. The highlight of the evening was when Ian, with the help of the audience, created a poem about "The Duchess". As the poem evolved it was illustrated by the cartoonist Tony Husbands, who has had cartoons published in many newspapers and magazines including *The Times* and *Private Eye*. There was much laughter from the 82 people in the audience.

The event, which raised £300 for **Colostomy UK**, was organised by Tim Smith who has a stoma himself and has been responsible for several fundraising bowls matches in aid of **Colostomy UK**. Thanks so much, Tim, as we know how much time and effort it takes to organise an event like this.

Thanks also goes to Ashfield House Vets, Long Eaton, and Blue Sky Black Labrador Dog Training and Food supplier, without whose support the evening would not have been possible.

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Tony Husbands (left), Ian McMillan (right) with Tim Smith and Rosemary Brierley (representing Colostomy UK).

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Thank you

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

Brian Chalmers

In the last issue we told you about **Brian Chalmers** who was planning to walk over the new Quensferry Crossing to raise funds and awareness for **Colostomy UK**.

Brian managed to raise over £500 and in his own words "had a fantastic day, to be able to do something I did 54 years ago when the Forth Road Bridge opened was unbelievable and humbling especially after having my stoma bag."

Susan Clements ran the Glasgow Half Marathon in October and raised over £400.

Adele Louth is competing in the Sheffield Half Marathon in April. If you would like to support her as she raises funds for **Colostomy UK**, You can donate through this link **https://www.justgiving.com/fundraising/adele-louth**

Each year the **Erewash Indoor bowls club** hold a fundraising day for **Colostomy UK**. Through a combination of raffle entries and Team subs they managed to raise a brilliant £75.

Gay and Gary Chalkin raised £423.50 from a Charity Garden party

Unity Lottery

unity

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

Members have the chance of winning a main prize of £25,000 each week (plus a £2,500 donation to **Colostomy UK**), as well as smaller prizes of five free draws, £25, and £1,000. Entry is only £1 per week and we receive 50p for every £1 ticket sold. You can join by completing the form on page 36 or online by visiting **www.unitylottery.co.uk** but remember to link to our Charity.

Grants and Trusts

We are grateful to the following charitable trusts and foundations who have recently donated to **Colostomy UK**:

The Vandervell Foundation, The Persula Foundation, The Colefax Charitable Trust, The Stella Symons Charitable trust.

Textgiving

You can now make a donation to **Colostomy UK** with a text message!

Whatever mobile network you're on, simply text our unique code **CASS01** and an amount of £4, £5 or £10 to **70070**.

Donating via text is free. There is no cost to you for sending the text message and your free allowance or bundle will not be affected – the only charge will be the donation itself.

What's more 100% of your text donation (including Gift Aid) will be sent to **Colostomy UK**.

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

Leave a Legacy

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

What your gift means

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

- Ensure there is always a voice at the other end of the phone.
- Train volunteers to provide support at open days and in hospitals.
- Fund our campaign for a stoma friendly society.
- Make sure the ostomates of tomorrow receive the same support from us that you have.

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 our Charity.

Make a donation

Colostomy UK

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

I would like to make a donation of:

☐ £15 ☐ £20 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 ☐☐/☐☐ Start date (Maestro only) ☐☐/☐☐ Issue No. (Maestro only) ☐☐

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 £15 becomes £18.75 with gift aid, at no extra cost to you.

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

Signature: Date: / / 2018

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

To the Manager: (Bank or Building Society)

Bank Address: Postcode:

Name(s) of Account holder(s):

Account number: Sort code:

I would like to make a regular donation* of ☐ £15 ☐ £20 or other amount (please state) £

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

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

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

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

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

Name: (IN CAPITALS)

Signature: Date: / / 2018

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

How we communicate with you: we believe in being open, honest and transparent with our supporters because we want you to feel comfortable about your decision to give and how Colostomy UK will contact you in the future.

I am happy for Colostomy UK to contact me by: ☐ Post ☐ Telephone ☐ Email ☐ Text message

You can change how we communicate with you at any time. Call us on: **0118 939 1537** or email: **info@ColostomyUK.org**

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

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

Registered with FUNDRAISING REGULATOR

Registered Charity No: 1113471

Stoma Care Open Days

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

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

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

Pelican Patient Event
Miskin Manor Hotel & Health Club,
Talbot Green, Pontyclun, nr Cardiff,
S Wales CF72 8ND
17 January 2018 1pm–4pm
Nathan Williams 029 2074 7000
nathan.williams@pelicanhealthcare.co.uk

Coloplast Event
Riverside Museum, 100 Pointhouse Road,
Glasgow G3 8RS
27 January 2018 12:00pm–3:00pm
Rebecca: gbrpr@coloplast.com

Salts Patient Day
Worcester Warriors Rugby Club,
Sixways Stadium, Warriors Way, Worcester,
Worcs WR3 8ZE
09 February 2018
Oliver Eagle 07768024376
oliver.eagle@salts.co.uk

Salts Patient Day
The Park Inn, Mansfield Road,
Nottingham, Notts NG5 2BT
20 February 2018 10am–2pm
Helen Sale
helen.sale@salts.co.uk

Salts – Darlington Stoma Support Group
Harrowgate Club & Institute,
Salters Lane North, Darlington,
Co. Durham DL1 3DT
21 February 2018 6pm-7.30pm
Kim Lemon 07721 556 136
kim.lemon@salts.co.uk

Salts Open Day
Ormesby Hall, Ladgate Lane (in marquee)
Ormesby, Middlesborough TS3 0SR
06 March 2018 10am–2pm
Kim Lemon 07721 556 136
kim.lemon@salts.co.uk

Salts Patient Day
The Steam Museum, Fire Fly Avenue,
Swindon, Wiltshire SN2 2EY
09 March 2018
Jonathan Tait
jonathan.tait@salts.co.uk

Salts Patient Day
The Cresset, Rightwell, Peterborough,
Cambs, PE3 8DX
21 March 2018 10am–2pm
Helen Sale
Helen.sale@salts.co.uk

Salts Healthcare
Hilton Garden Inn, Vaux Brewery Way,
Sunderland SR5 1SN
19 April 2018 10am–2pm
Kim Lemon 07721 556 136
kim.lemon@salts.co.uk

Information about forthcoming Open Days in your area may be sent to you by **Colostomy UK**. These invitations are sent by our volunteers, who stick an address label on the envelope. The company involved provides the stamps or pays the cost of postage and pays an administration cost which helps to boost **Colostomy UK** funds. Your personal details are never disclosed.

National Support Organisations

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

IA The Ileostomy and Internal Pouch Support Group
www.iasupport.org
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 01202 674336
e-mail info@mitrofanoffsupport.org.uk

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 240253
e-mail info@breakawayfoundation.org.uk

Support Organisations for associated medical conditions

Beating Bowel Cancer UK
www.beatingbowelcancer.org
Telephone 020 8973 0000

Bowel Cancer UK
www.bowelcanceruk.org.uk
Telephone 020 7940 1760
e-mail admin@bowelcanceruk.org.uk

Macmillan Cancer Support
www.macmillan.org.uk
Telephone 0808 808 00 00
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

News from Local Support groups

Cornwall Ostomy Support

Location: Carnon Downs, Village Hall.

Date: First Tuesday every month.

Time: 14:00 till 16:00.

Facebook Group: Cornwall Ostomy Group, great on line support group.

Membership: Total membership of 112 ostomates, with attendance of around 35 people per month. No membership fees.

Events: As well as meeting monthly we organise a large number of events throughout the year including open days with stoma care companies. Our last event at Hayle had in excess of 300 ostomates attend. We also work very closely with the stoma nurses at Treliske Hospital.

On the social side we hold our monthly quiz night on the third Wednesday of the month. Christmas lunch last year was at the Falmouth Hotel. We also organise various social outings each year.

Cornwall Ostomy Support, Group Photo

For more information please contact: Ken Jones **01872 863 106** or e-mail: **kenjones1808@gmail.com**

SHROPSHIRE B.O.T.s (Bums on Tums)

Shropshire B.O.T.s (Bums on Tums) Support Group held their second Open Day on October 12 and once again the day was a great success with over a 100 visitors.

This, of course meant they were in a position to donate a healthy:

- £600 to Stoma Aid to help them to continue with their excellent work in sending unwanted stoma products to those in need abroad.
- £100 was also donated to The Ileostomy Association who had a stand at the Open Day.
- A further £50 was given to a small local group, Disability Oswestry, who produce a directory of voluntary groups in the Oswestry area.

The group would like to thank a number of people who helped make the day such a success: "Firstly, the members of the Group who welcomed the public to the event, sold raffle tickets, made copious cups of refreshments and looked after all attendees. Thanks are also extended to The Rt Hon Glyn Davies MP, who gave an interesting and amusing insight into his journey and life with a stoma. Not forgetting Helen Bracey from ConvaTec, who is a good friend to the B.O.T.s, and whose talk on Diet and Nutrition was very well received by all who heard it. A big thank you too to the brilliant stoma care nurses from The Royal Shrewsbury Hospital and Wrexham Maelor Hospital who gave our leaflets to patients in their clinics and who are very supportive of our Group. Last, but no means least, thank you to all the members of the public who turned out, because without you there would be no event".

Mike Tomkins doing an excellent job of manning the stand

The 2018 B.O.T.s Open Day, will be announced in the next *Tidings* edition.

The Shropshire B.O.T.s (Bums on Tums) Support Group meet every second Thursday of each month. From 14:00 until 16:00 in the Memorial Hall, Oswestry, Shropshire, SY11 2EG.

For more information please contact Irene Constable on 01691 238 357.

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

Stoma support groups
in your county

Channel Islands

Guernsey
Guernsey Ostomates
Luci Deane 0148 123 6077 / lucideane58@gmail.com

Jersey
Jersey Ostomy Society
Fiona Le Ber: 0153 4445 076 or jerseyostomysociety@gmail.com

England

Bedfordshire
Saturday Social Club
Karen Richards: 0123 479 2278

Berkshire
E.B.O.C (East Berkshire Ostomy Club)
Jackie Dudley: 0134 442 6652

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

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

Buckinghamshire
Milton Keynes Stoma Association
Thia Cooper 01908 679 295 / mksa.chair@gmail.com

You Are Not Alone Stoma Support Group
Carla 0784 6354 918

Cambridgeshire
Connections Cancer & Colostomy Group
Bev or Sue Scott 0135 386 0356/ 0776 695 8811 or Barbara Hunt 0135 386 2133

Peterborough Stoma Support Group – Ostomistics
Alan Wright 0135 465 3290 / 0783 666 1102
http://www.ostomistics.org/

Cheshire
Countess of Chester Hospital Stoma Support Group
Stoma Nurses 0124 436 6170

East Cheshire Stoma Support Group
Catherine McIntosh: 01477 535 071

Stockport Support Group
Angela Simpson: 0161 320 9400 / 0800 652 6667

Warrington Ostomy Support Group
Jane Shaw: 0192 566 2103

Cleveland
Oops Group
Julie Morrisroe/Carol Younger: 0128 728 4113

County Durham
Bishop Auckland Stoma Care Group
Betty: 0138 881 4535 or email: pgill82171@aol.com

Darlington Support Group
Sister Jacqui Atkinson: 01325 743005

Durham Stoma Support Group
Katie: 0191 3332184

Cornwall
Cornwall & Plymouth Bowel Cancer Support Group
The Chairperson: 01726 828 419 or 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 Support Group
Mandy Rowe: 01726 832 642
E: murphy.rowe781@btopenworld.com; Henry Kendall: 01208 850 986 E: h.kendall380@btinternet.com or Anna Rennie: E:anna@thesilverocean.com

Cumbria
Grange Cancer Support Drop in
Marie: 0153 953 3279

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

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

Derbyshire
Diverted Local Stoma Support Group
Diane Manning: 0128 354 1311

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

Mid Devon Ostomy Support Group
Janice: 07923 975 051 or 01363 776 417 or jdkelly234@gmail.com

Plymouth & District Bowel Cancer Support Group
Wendy Wilson or Keith Anderson: 07934 922 156 Facebook: Plymouth Bowel Cancer

Dorset
Colostomy Urostomy Pouch Ileostomy of Dorset – CUPID (Bournemouth)
Beryl Andrews 0120 248 3303

Colostomy Urostomy Pouch Ileostomy of Dorset – CUPID (Poole)
Jenny Pipe: 0120 274 0440

Colostomy, Urostomy, Pouch & Ileostomy of Dorset – CUPID (West Dorset)
Colin Clare – 0130 585 3238

East Midlands
Newhall Stoma Support Group
Diana Manning: 0128 354 1311 or Helena: 0793 233 1850

Essex
Connect
Lin Hart 0127 950 5273 email: comeconnectwithus@gmail.com

Mid Essex Stoma Support Group
Paul Foulger: 0124 522 4374

N.E.S.S (North Essex Stoma Support)
Secretary: Brian Waller: 0120 654 0449

Optimistic Ostomates
Carol Booth: 0170 238 5510 or Angela Taylor: 0170 238 5509

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

STEPS
Jackie: 0126 845 1937 or email: stepsessex@gmail.com

Gloucestershire

Ladies Big Op Group
Gill Hopkins: 0300 422 4363. Please Note: For ladies with one or two permanent stomas

Vale Stoma Support Group
jfn.dursley@gmail.com or text 0794 182 7393

Hampshire

Solent Ostomates Support Group (S.O.S.)
Sally: 07527 707069

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

Replummed stoma support group
For contact details please visit www.replummed.me

Waterside Stoma Support Group
Hazel Derham: 0238 089 1934 or hayjuder@sky.com

Wessex Urology Support Group
Adrian Kuczynzki: 07910 786 978

Herefordshire

Herefordshire Stoma Support Group
Carol Steele 0143 288 0656 or email: carolsteeleglo@gmail.com

Hertfordshire

Colonise
Anastasia 0172 776 0981

Stevenage Ostomistics
Judy Colston: 0143 835 4018 / neilcolston@btinternet.com or Alfred: 0176 731 6958

Isle of Man

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

Stoma Support Group
Carole Cringle stoma nurse: 0162 465 0212

Kent

Ashford Stoma Support Group
Carole Hobbs: 0130 381 4014 or Margaret Webb 0123 362 8807

Atoms Support Group
Maria Culleton, SCN: 0122 776 9679 or 0782 799 7424

Dartford Ostomy Group Support (DOGS)
Tracey, John or Sue: 0794 897 4350 or dogs-uk@hotmail.com

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

M.O.G.S (Medway Ostomy Group Support)
Helen Or Tracey: 0777 360 5534

Maidstone Stoma Support Group
Judy/Kirsty: 0162 222 4305

Royal Tunbridge Bowel Cancer Support Group
Bronwen Tetley CNS: 0189 252 6111 x 2287

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

SWAN Stoma Support Group
Heather: 0771 144 5312

Thanet Stoma Buddies Support Group
Kathy 0184 329 1825

Lancashire

North Manchester and Bury Stoma Support Group
Julie Meadows (SCN) 0161 720 2815 or 0784 120 6910

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: 0116 239 2844 / kosg2013@btinternet.com

Lincolnshire

Friends East Coast Support Group
Betty: 0120 572 4120, Sheila: 0120 536 4493

Grantham Support Group
Bobbie/Rachel: 0147 646 4822

Sutton Bridge and Long Sutton Ostomy Group 0140 635 1617

London

Bowel Cancer Newham
Scyana: 0208 553 5366 scyana@tiscali.co.uk

Homerton Hospital Bowel & Stoma Support Group
Angela Davy: 0208 510 5318 or 0208 510 7599

Rectangle – Colorectal Cancer Support Group
Regina Raymond 020 7472 6299

South Woodford Support Group
Nurse Christina and Lisa: 0208 535 6563

Surrey & South London Bowel Cancer Support Group
Sue Berry: 0173 755 3134 or John Amos: 0208 668 0796

Merseyside

I.C.U.P.S
SCN: 0151 604 7399

St Helens Cancer Support Group
Office: 01744 21831, Denys Floyd: 01744 884097 or email: contact@sthelenscancersupportgroup.org

Middlesex

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

Norfolk

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

STARS (SToma And Reconstructive Surgery social support group)
Sylvia Hughes 01263 733448 sylvia.ruth.hughes@gmail.com

Northamptonshire

Northampton Ostomy Support Group
Ian: 0780 1316 403 (evenings) or Trish 0770 3188 386

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull: 0771 447 9320

Hexham Ostomy Group
Judith on 0796 792 7286

Northumberland Cancer Support
members@northumberlandcancersupportgroup.co.uk

Notthinghamshire

North Notts Stoma Support Group
Tore and Nicky Norman: 0177 371 5460

Nottingham QMC Stoma Support Group
Rosemary Brierley: 0115 982 6691

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

Shropshire

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

Staffordshire

Outlook
Moira Hammond 0778 840 2195

Suffolk

East Suffolk Ostomy Group
Marion Fisher: 0147 331 1204

James Pagett Ostomy Support Group (Afternoon Meeting)
Vicki Blackwell on 01493 663363

James Pagett Ostomy Support Group (Evening Meeting)
Sandra Hutchings: 0150 258 5955

L.O.G.S (Lowestoft Ostomy Group Social)
Mandy O'Shea: 07899 913 617 or Bruce Pollard: brucepollard@me.com

West Suffolk & District Stoma Group
Jessica Pitt stoma nurse: 0163 851 5525

Surrey

Epsom and District Stoma Support Group
Lindsay, Trevor or Sheena: 0137 273 5925

Normandy Colostomy Support Group
Marina Harkins: 01483 233 126 or 07852 554 049 or Jackie Sanders: jackie-sanders@hotmail.co.uk or 07815603742. Website: http://www.normandystomagroup.wordpress.com

Stoma Support Group
Robin Young: 01428 723 255

Sussex

Brighton & District Support after Stomas (SAS)
Sylvia Bottomley: 0127 355 4407

Chichester Stoma support Group
The Stoma Care Team 0124 383 1527

The Ostomy Friends Group
Jane Quigley: 0132 341 7400 ext 4552

West Sussex Princess Royal Stoma Support
Tina Walker: 0144 444 1881 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 Molineaux Centre
John Burchell 0191 265 1047

Royal Victoria Infirmary Support Group
John Burchell 0191 265 1047

Warwickshire

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

West Midlands

Coventry Stoma Support
Martin: 0794 738 5643

Wiltshire

Swindon IA
www.swindon-ia.org.uk

Wessex Stoma Support Group
Michael Slater: wessex.stoma@yahoo.co.uk or on 0172 274 1233

Worcestershire

Kidderminster & District Collossus Support Group
Brendon Drew: 0129 940 0843

Yorkshire

Acorn Ostomy Support Group
Michelle: 0758 069 3155 (After 6:00pm)

Airedale Stoma Support
Sue Hall: 0153 564 6373

Barnsley Bottoms Up Stoma Support Group
Stoma Nurses 0122 643 2528 or Celia Utley (Chairman) 0122 628 4262

Behind You (Calderdale & Huddersfield Bowel Cancer Support Group)
Stoma Care Nurses: 0148 435 5062

Dewsbury & District Ostomy
Janet Edmond: 01924 512 041 or 01924 512 072

Hambleton and Richmondshire Ostomy Support Group
Stoma Care Nurses – Judith Smith and Mary Hugil 01609 764620 / 07736 295131

Harrogate Stoma Support group
Jacquie: 07768 024356

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: 0798 956 5335 or Pete Rennard: 0793 951 8642 / 0148 279 3966 or Rosanna Grimsby: 0148 280 1575. www.hercosg.org.uk

Northern Ireland

County Armagh

Craigavon Area Hospital
Clare Young/Lynn Berry/Janice Garvie 0283 861 2721

Daisy Hill Hospital Support Group
Bernie Trainor: 0283 083 5000 Ext 2222

County Down

North Down Stoma Support Group
Adrian Ewing on 0785 074 1511

Ulster Hospital
Hazel/Martina: 0289 055 0498

County Londonderry

Causeway Support Group
Mary Kane: 0287 034 6264

Republic of Ireland

Dublin

Bowel Cancer Support Group (ICS)
National Cancer Helpline: (00 353) 1 800 200 700 or Olwyn Ryan: (00 353) 1 231 0500

County Mayo

Mayo Stoma Support
Marion Martyn: 094 902 1733

Northern Ireland

County Antrim

Colostomy UK Volunteers Northern Ireland
Chris Wright: 0772 071 7771

Mater Hospital
Karen Boyd – Stoma Nurse: 0289 074 1211 Ext 2329

Royal Victoria Hospital – Belfast
Sarah Haughey/Audrey Steele: 0289 024 0503 Ext 3483

Scotland

Ayshire

Ayrshire & Arran Stoma Support Group
Jim Krasewitz: 0129 222 0945

Stoma Care And Recovery (SCAR)
Maggie: 0129 427 1060/ 0781 773 6147 maggie13@sky.com or Rhona: 0129 455 7478

Fife

Fife Ostomy Support Group
Ishbel Barr: 0159 277 2200

Lanarkshire

Glasgow Stoma Support group
Chairperson: 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 0145 037 4012. Fiona Gentleman: r.gentleman@sky.com or 0145 037 1063

West Lothian

GOSH (West Lothian)
Scott Pattison: 07502 163 644

Wales

Bridgend

Bridgend Ostomy Patients Support Group
Anita Brankley (Secretary) 0165 664 5602 or bridgend.ostomy@gmail.com

Carmarthenshire

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

Conwy

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

Flintshire

Bag For Life Stoma Support Group In.It.Together
Faye Jones 0785 275 0772

Gwent

Blaenau Gwent Self Help
Celia McKelvie: 0187 385 2672 After 6pm

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

Mid Glamorgan

C.A.S.S Colorectal and Stoma Support Group
Colorectal Nurse Team on 0168 572 8205

Pembrokshire

PSA (Pembrokeshire Stoma Association)
Roy Whitfield 0143 776 0701

Powys

The Bracken Trust Cancer Support Centre
Helen Davies: 01597 823646

Rhondda Cyon Taf

Royal Glamorgan Stoma Care Support Group
Domenica Lear 0144 344 3053

Swansea

Swansea Ostomy Self Help Group
Glynis Jenkins: 0179 241 8245


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- A closed Facebook group for supporting each other and exchanging hints and tips
- A website packed full of practical information

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