

ESTEEM[®] (Soft Convex

I'm worrying less about leakages, and enjoying life more.



SOLUTION





ESTEEM[®] (Soft Convex

One piece stoma solutions designed to move with your body

Ideal for those with uneven skin surfaces around the stoma.

The shallow soft convex ring

provides more flexibility. The unique hydrocolloid baseplate helps prevent irritation which reduces the risk of leakages and provides that little extra support needed to help you feel secure and confident.

Have a hernia?

CA-SC-AD-0120

The Soft Convex baseplates* may provide a great fit. *If you are unsure, always refer to your stoma nurse

To request your free samples of Esteem[®]+ Soft Convex, please complete the form below and return in an envelope to **FREEPOST CONVATEC**. We may need to call you to ensure product suitability.



Title	First Name				Last Name
Daytime Phone Nu	mber				
Address					
					Postcode
Last Stoma Surger	y Date _{момтн}	/	YEAR		We collect this information to ensure we direct your enquiry to the right team of experts
Email				Signatur	e

Yes, I would like to receive **FREE** samples, please contact me on the number above, should you need to.

Under the General Data Protection Regulation ("GDPR") we are required to let you know about how ConvaTec Limited process your personal information. We must also let you know that you have a number of rights relating to your personal information, for example, you have the right to request a copy of the information we hold on you at any time, or seek that we verify, amend or delete that information. You also have the right to complain to the data protection authorities if you have any concerns about how we handle your personal data. All this information can be found in our Privacy Policy which is located on our website at https://www.convatec.co.uk/about-us/privacy-policy. Alternatively, we can send you a copy in the post if you tick the box at the bottom of this page.

If you no longer wish to receive marketing communications from us, please indicate by ticking the box provided.

If you have any questions on how we process personal information, you may contact the ConvaTec Group Data Protection Officer by email at dataprivacy@convatec.com; by post at Floor 7, 3 Forbury Estate, 23 Forbury Road, Reading RG1 3JH; or telephone on O118 952 8100.

Advanced Filter minimises odours and ballooning

Inspection window to ease application, ideal for quick checks whilst wearing

Tapered Convex

baseplates soft, flexible and skin-friendly, designed to reduce the potential for leakages

Soft cover on both sides for added comfort provides quiet and nonclinging fabric Fluidresistant filter for extra leakage protection

All baseplates have tapered edges

CE 9

A range of stoma size options

ESTEEM® 🕑 Soft Convex

Available as a CLOSED and also DRAINABLE bag which features a Safe Seal clipless closure and wipeable tab for cleaner, easier bag drainage.

Complete the enclosed enquiry form and return **FREEPOST**



ORDER YOUR FREE SAMPLE





Dear readers

Editorial Team

Editor, Writer & Researcher Richard Biddle General Manager Libby Herbert

Colostom

Colostomate & Volunteer Jackie Dudley

Colostomate & Volunteer Rosemary Brierley

Data Analyst & Publishing Arvind Anand



Patient information awards Highly commended

*British Medical Association Patient Information Awards 2019.

Tidings Magazine:

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

Disclaimer:

The display, description or demonstration of products and services or the inclusion of advertisements, inserts and samples within Tidings Magazine does not constitute an endorsement or recommendation of these products and services by Colostomy UK.

©Copyright 2019 Colostomy UK. All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, except as permitted by the UK Copyright, Designs and Patents Act 1988, without the prior written permission of the publisher. All marks acknowledged.



It's that frantic time before Christmas when everyone is in headless chicken mode. I hope the arrival of *Tidings* will give you an excuse to put your feet up for an hour or two! Regular readers may have noticed that this year's winter edition is slightly earlier than usual. This was deliberate on our part, as we felt that you might prefer to receive it before, rather than after the Christmas break. It also means that future editions (spring, summer and autumn), will be slightly earlier now too. Those particularly observant amongst you will have also spotted something different about this edition's front cover... I am very proud to announce that *Tidings* won highly commended at the British Medical Association Patient Awards this year. Rosemary Brierley accompanied me to the awards ceremony in September. This was very fitting, given her many years of work for **Colostomy UK** and *Tidings*, including a couple of lengthy stints as editor.

2019 has been an exciting year for **Colostomy UK**. As well as developing and enhancing the ways in which we support ostomates, we have been able to devote more energy to campaigning. The latter is already paying dividends; we now have a 'voice' at many of the airport accessibility forums, which is helping us to shape things at a policy level. We have also seen some changes to our board of trustees. Rather than say more here, I encourage you to read Libby Herbert's thoughts on the year and, as **Colostomy UK's** general manager, let her introduce our new trustees and thank those who have left us (page 8). Giovanni rounds things off by reflecting on what we have achieved with Active Ostomates (page 30) and fundraising in 2019 (page 36).

As you will know from last edition, a lack of reader's questions has recently prevented us from running Dear nurse. Well thankfully, it seems that our idea to broaden things out and include other healthcare professionals has worked. On page 12 you will find 'Dear dietitian'. Please keep those questions coming! Whilst on the subject, I also want to say a big thank you to Julie Rust and on behalf of **Colostomy UK** wish her all the best for her retirement. Julie has answered our Dear nurse letters over many years, dispensing invaluable advice to thousands of people. You can read more about her career and all she has contributed to the ostomate world on page 20.

So, what else is in this edition? We have an excellent article about parastomal hernias and supportwear. Ambra Bertinara, who is a stoma care nurse specialist in Nottingham, has contributed a 'back-to-basics' piece on irrigation, which I am sure will be useful for 'beginners' and anyone considering this method of stoma management. There are also three real lives' stories to enjoy. Jenny Hill talks about the events of the past year or so and how she now finds herself at the point of considering a reversal. Iola's inspirational story reminds us that young people have stoma surgery too. Finally, we have a lighter piece all about how one reader is carving a career contributing jokes and anecdotes to Radio 5. It's the *Tidings* equivalent of a Christmas cracker!

Merry Christmas everyone and a happy new year!

Richard Biddle Editor, Writer & Researcher

TIDINGS 56 | WINTER 2019 | 5

SUPORTX WISHING YOU A VERY HAPPY AND PROSPEROUS 2020!

Suportx are the leading manufacturers and suppliers of hernia/abdominal support garments in the UK. We offer a complete service from fitting to delivery of your garment.



AVAILABLE ON NHS PRESCRIPTION FROM YOUR GP

Suportx offer a **FREE** nationwide fitting service for all hernia support garments call or visit our website on:

0800 917 9584

(0) www.suportx.co.uk



Contents



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

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

How to contact us

Stoma helpline for:

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

Adminline for:

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

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

info@ColostomyUK.org

Editorial Enquiries

Letters, articles or other submissions

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

info@ColostomyUK.org

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

Arvind.Anand@ColostomyUK.org

Social media:

Find us on Facebook

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



Colostomy UK news

8 Colostomy UK: news

Real lives

- 10 My name is Iolo Edwards and this is my stoma story Iolo Edwards
- 14 Living with the 'Creature' Jenny Hill
- 27 Listen out for Colin from Cheltenham on Radio 5 Colin Williams

Wellbeing

- 12 Dear dietitian: What is Kefir and is it safe for ostomates? Sophie Medlin
- 22 Irrigation and you: The basics Ambra Bertinara
- 30 Colostomy UK: active ostomates®
- 35 SUPPORT GARMENTS Lisa Tate

Fundraising

36 Colostomy UK: focus on fundraising

Support

- 17 Your letters and e-mails
- 20 A huge thank you! Rosemary Brierley
- 40 News from support groups across the UK
- 41 Stoma care open days
- 41 National support organisations
- 42 Stoma support groups in your county

New products

26 New products and services

Donating to Colostomy UK

An annual donation of £20 (or whatever you can afford) allows us to produce *Tidings* and to continue our vital work, supporting, and empowering ostomates – see page 38 for donation form.

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

Colostomy UK: news

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

Happy Christmas to all!

2019 has been a great year for **Colostomy UK** and this being the season of celebration, I wanted to take a moment to reflect on where we've got to, and to say a massive thank you to everyone – employees and volunteers – for everything they've done in the name of people with stomas and hidden conditions more generally.

The heart of our charity

We couldn't offer support and advice to people with stomas (or their families, carers and friends) without our volunteers. We now have nearly 100 volunteers, with another 40 in the process of joining Team Colostomy UK. We also recruited Emma Howell this year to look after them. On both Emma's and the charity's behalf, I'd like to thank all our volunteers for their time, commitment and support. Your expertise, your care and the quality of your advice, is invaluable. Whether speaking to ostomates who call the helpline, supporting at an open day, being part of the Facebook private group, a member of the Tidings editorial team, or ensuring the governance of our charity: you are the heart of **Colostomy UK.** We are extraordinarily fortunate to have each and every one of you as part of our team!

Partnering effectively

A huge part of what we do is trying to ensure that people with stomas are treated with respect as they go about their daily lives. We call this our campaign for a 'stoma-friendly' society. There have been many highlights this year. Regular readers of *Tidings* will know that we have further developed our active ostomates initiatives (you can read how on page 30). We have continued to champion accessible travel (see below). We have also worked with more organisations than ever before, acting as their 'critical' friends by helping them to ensure they become more inclusive. We have also been collaborating with healthcare professionals and other charities to see where we can complement one another's work.

Indeed, we are engaging more than ever before with healthcare professionals all over the UK. The Windsor, Ascot, Maidenhead and Slough Stoma Support Group (WAMS) is an excellent example. At the end of 2018 we approached Liz Harris, who is a stoma care nurse at Wexham Park Hospital, asking her what we as a charity could do to support ostomates in her community. She said they needed a support group and so WAMS was born. Thanks to the hard work of Liz and **Colostomy UK's** Giovanni, the first meeting of this volunteer–run group took place in the spring of 2019.

In 2019 we also began working with a number of NHS trusts to set up ostomateto-ostomate buddy systems for their stoma care departments. Watch this space!

Power to all

Through support groups, individuals, stoma care nurses, stoma care companies, and care homes across the UK – from Derry in Ireland, Glasgow in Scotland, right down to Devon in England – we have organised in excess of 116 sessions, games, challenges and workshops from our active ostomates initiatives, reaching more than 4,000 people directly. As a whole, the initiatives have empowered ostomates to return to sports, hobbies and other interests, and given them the confidence to take up new challenges. Once again, I'm extremely grateful to all who took part and made this happen.

Getting the message out there

We have continued to campaign and be the ostomate voice on the bigger issues, raising

awareness and encouraging organisations to make their facilities more inclusive. One area where we have been especially active in 2019 is championing accessible travel at UK airports. As well as being active members of the accessibility forums at Edinburgh, Manchester, Luton, Stansted, Birmingham, Bournemouth, Cardiff. Heathrow and Gatwick airports, we are now influencing the training of airport staff. Equally, we have worked with a number of organisations to make their accessible toilets stoma-friendly. This year we have also been much more proactive on social media, helping to spread the word that stomas have the capacity to improve the quality of people's lives.

Going forward

We will always run our helpline, produce informative literature, manage our Facebook private group, publish *Tidings* and attend open days to give face-toface support. And we will continue – with the support of our volunteers – to work hard to partner, influence, and empower in the name of all ostomates. However, we are keenly aware of the need to keep evolving as a charity, so that we can reach more ostomates to offer them support and advice in new and effective ways. The coming year promises to be just as exciting as 2019...again, watch this space.

Some new faces

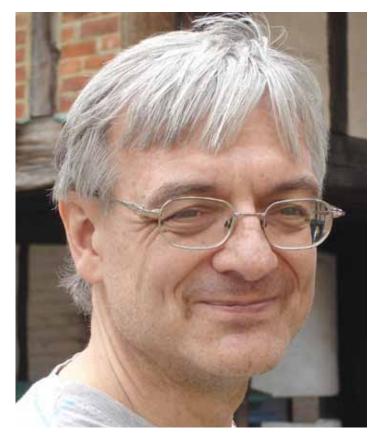
2019 also saw some changes to our board of trustees. We said a big thank you to Ernie Hulme, Ian Jackson, Sarah Squire and Peter Martin, for all their efforts over the years and wished them well for the future. In autumn we welcomed David Buchan and Steve Scoffield, both of whom you can read about opposite.

> Libby Herbert General Manager





David Buchan



Secretary and Governance Trustee

David was brought up in Surrey, lived in London for many years, and is now back in Surrey with his wife Cynthia. They have three grown–up children. David spent most of his career in central government as an auditor and civil servant. He retired in 2019, finishing as a senior civil servant in the Department for Transport.

David brings to **Colostomy UK** a wealth of experience. He has served as a trustee for a number of small charities and is currently undertaking a diploma in the Charities Programme run by the Cass Business School. If that wasn't enough, he also works part-time as Operations Director in his parish church, where he brings his skills to bear running finance and human resources and gives advice to the Parochial Church Council on matters relating to how a charity should be run.

David's connection with **Colostomy UK** is through his mum, who had emergency surgery back in 2014. She likes to keep as active as possible, including trips to historic places with family and friends. Like most ostomates her first question is often: "what are the toilets like?" This has helped David appreciate the issues people with stomas face in their day-to-day lives.

David hopes his understanding of transport networks will be useful as **Colostomy UK** continues to campaign for a stoma-friendly society. But his immediate focus is on understanding the issues we face as our charity continues to grow and helping to ensure that **Colostomy UK** is managed in line with the best principles of charity governance.

Steve Scoffield



Finance Trustee

Steve was born in Worcester and lived in north Worcestershire until moving to Devon in 1999. He is married to Cathy. They have two grown–up daughters and two grandchildren, all of whom live within 100 yards of each other.

Steve qualified as a chartered accountant in 1984. After 15 years in general practice he was appointed Director of Finance for the Lee Abbey Movement, a charity group based in North Devon. In 2010 he moved on, joining the National Autistic Society. Steve is currently the Director of Finance for two small charities and treasurer of The Melanesian Mission. He also recently achieved the Institute of Chartered Accountants in England and Wales Business and Finance Professional designation. He thus brings considerable experience and technical expertise to **Colostomy UK**.

Steve suffered from ulcerative colitis as a teenager and was diagnosed with the early stages of bowel cancer in 2012. This led to a permanent ileostomy being formed. Prior to his stoma surgery, Steve was given some copies of *Tidings* by a friend and was encouraged to join our private Facebook group. He has subsequently found the support, advice and encouragement provided by **Colostomy UK** invaluable. He is looking forward to helping us improve the lives of ostomates.

My name is **Iolo Edwards** and this is my stoma **Story** Iolo Edwards



In mid-February last year, when I was 13 years old, I had my first symptom of what turned out to be inflammatory bowel disease (IBD). Some weeks later I suddenly became very ill, even though I didn't have many symptoms. On 25 March I was admitted as an emergency into Prince Charles Hospital. Three days later, when all types of infections and bugs had been ruled out, I was blue lighted to Noah's Ark Children's Hospital. By this time, I had lost a huge amount of blood and my weight was dropping. The doctors thought I had ulcerative colitis.

The doctors at Noah's Ark tried different treatments including steroids and infliximab, but nothing seemed to work. On Friday 6 April me and my parents were introduced to the surgeons and we discussed the surgery that was going to happen the following Wednesday if I did not improve. Over that weekend, I got much worse. The consultant came in to see me and my parents on the Monday night and told us they would be doing the surgery the following day. My Consultant told my mother that my family should spend time with me in the morning because I had become critically ill.

The surgery lasted over seven hours. It worried everyone that it was going on for so long. My parents were upset and even the nurses on the ward were upset, but in the evening I went to the recovery room and everyone was relieved. My stoma started to work straight away, which my doctors were really pleased about. After nearly a month in hospital I was able to come home. Since the surgery I have suffered with other problems linked to IBD. These are annoying, particularly as they restrict some of my activities and hobbies, but I try to be very positive as much as I can.

Before I went back to school my parents and I had meetings with my head of year and form tutor and the school nurse. We inspected the disabled toilets, but as these were being used by the teachers, they were a bit grubby and I did not want to consider doing a bag change in there. Then there was the possibility of me needing to get access quickly if I ever had a leak and if there was a teacher in the toilet, it would mean I would need to wait. so it was decided the school would give me a private room. There was an old upstairs washroom that the school fitted out with a locker, a mirror, a

shelf and a bin and the toilet was fitted, so it was all nice and clean. It has a code lock, which only me and the cleaners and the headmaster have the code for. School even asked me if I wanted to pick my own paint colour - so I went with plain white!

School were very good about how much time I missed in the first few months.



Richard Branson and Kate Winslett with Iolo while on holiday at Es Castell, Port Mahon, Menorca



In the last year I have only managed to do half days. Any lessons that I haven't been present at the teachers send to me electronically via Google Classroom, which means I have not dropped behind too much in my studies.

All the medical people who look after me have been really surprised at how quickly I have bounced back, how well I have got on with things and how I want to help in any way I can to let people know that having a stoma is fine and won't stop you doing anything. I have helped my consultant give talks to medical students on IBD. I have attended a lobby with Crohn's and Colitis UK (CCUK) at The Senedd (National Assembly for Wales) on funding for more nurses and specialist staff. I have taken part in family days where I have contributed by telling my story to the room, so I can share what has happened to me. I want to do as much as I can to get the message out about what living with medical conditions can be like.

Before I was ill I did not involve myself with charity at all, but after what happened to me, I want to get involved with some of the organisations that help people with IBD or ostomies. Over the last 12 months I have helped organise a quiz night which raised £600 for CICRA* and walked 5k in the Swansea "Walk It" for CCUK. When I was feeling better and more fitter, I wanted to do something big that would go towards CICRA and Noah's Ark Children's Hospital, so I did a bike ride that was 161km from my home town of Merthyr Tydfil, to Brean Sands. The ride took place on the 28 March, which was exactly a year to the day that I was taken into Noah's Ark. It was over two days and ended in time to join my old Rugby Club on their tour and I was joined by some of the other rugby boys and their Dads. I wanted to raise £1,500, but with all the sponsorship so far, have raised (with gift aid) over £6,800. I am proud that I was able to finish my bike ride and even do a couple of bag changes in the back of the support van!

Since the bike ride I have been asked to be an ambassador for Noah's Ark Hospital, which means a lot to me and my family because really it was the people there that saved my life. I will always do as much as I can to help, like joining their fundraising days and collecting for their shop. I have been able to support other peoples' efforts for the charity too, like starting their Great Welsh Walk event and getting two people to run the Cardiff Half Marathon in October on my behalf. It has been a very good opportunity for me to be involved with the hospital.

As much as possible, I try to not let what has happened to me and the problems that come with my illness affect what I do now and what I want to do in life, which is why I try to involve myself as much as possible in challenges. I think the main thing is not to let anything get me down and be honest with everyone about what has happened to me and what living with a stoma is like for me.

I hope people can take some positive things from my story.

*CIRCA is a national charity dedicated to supporting children and young people in the UK with Crohn's disease and ulcerative colitis. For further information visit their website: **www.cicra.org**



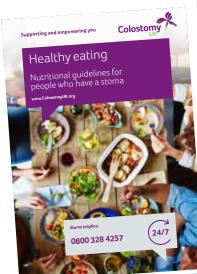
Thank you.

Dear dietitian

Ed's note: As you may recall from the last edition of *Tidings,* I mentioned that we were going to broaden Dear nurse, to encompass questions for surgeons and dietitians too. Well here is our first! As you will see it is about the benefits that one reader experienced after introducing kefir to her diet. But, as Sophie Medlin (Dietitian) tells us, it may not be suitable for everyone – so please read Sophie's advice before you try!

Please keep those questions and e-mails coming as we depend on them to run this feature. Any stoma-related questions that you would like to put to a stoma care nurse, surgeon, dietitian, GP or physiotherapist will

be gladly received.



For your complimentary healthy eating booklet, please contact us on: 0118 939 1537 or visit our website: www.ColostomyUK.org to download a copy.

1	
2	
5	
5	Dear Dietitian
-	Coping with digestive aftermath of colostomy
-	
0	A few weeks ago someone brought me a small amount a bit a few weeks ago someone brought me a small amount a bit culture of something called 'Kefir', that she said was a bit culture of something called 'Kefir', that s
-	A few weeks ago alled 'Kefir', that she sata with milk, culture of something called 'Kefir', that she sata with milk, like yoghurt and easy to make by just topping up with milk, tike yoghurt and easy to make be starter culture from the fresh straining in order to separate the starter culture from the fresh straining in order to separate the starter culture from the fresh straining in order to separate the starter culture from the fresh
-	like yoghun ander to separate the starter culture in again to make
~	like yoghurt and cut separate the starter cuture from to make straining in order to separate the starter cuture from to make kefir after a day or two, and then topping up again to make kefir after a day or two, and then topping up again to make refir after a day or two, and then topping up again to make
208	straining in order to sept and then topping up again to mealth or kefir after a day or two, and then topping up again to mealth or more. This was just a recipe idea: there was no talk of health or
-	mote, his in a medicine.
-	C. U.L. T chartea using
1	Within a very few days I had so much kefir that I stated it in all kinds of ways: smoothies, breakfast dishes, desserts, it in all kinds of ways: some away to friends and neighbours.
4	it in all kinds of ways: smoothies, breakfunds and neighbours.
1	cours. pancanet - J
	After about three weeks of this, I realised that the very After about three weeks of this, I realised that the very annoying and sometimes really awful digestive consequences annoying and sometimes really awful digestive and that
1	After upon and sometimes really awful algers ago and that
-	After about the sometimes really awful algestive annoying and sometimes really awful algestive of the colostomy that I had had seven years ago and that of the colostomy that I had had seven years ago and that seemed to be getting worse had ceased completely and a scalp seemed to be getting worse had ceased completely and a scalp seemed to be getting worse had ceased completely and a scalp seemed to be getting worse had ceased completely and a scalp seemed to be getting worse had ceased completely and a scalp seemed to be getting worse had ceased completely and a scalp seemed to be getting worse had ceased completely and a scalp seemed to be getting worse had ceased completely and a scalp seemed to be getting worse had ceased completely and a scalp seemed to be getting worse had ceased completely and a scalp seemed to be getting worse had ceased completely and a scalp seemed to be getting worse had ceased completely and a scalp seemed to be getting worse had ceased completely and a scalp seemed to be getting worse had ceased completely and a scalp seemed to be getting worse had ceased completely and a scalp seemed to be getting worse had ceased completely and a scalp seemed to be getting worse had ceased completely and a scalp seemed to be getting worse had ceased completely and a scalp seemed to be getting worse had ceased completely and a scalp seemed to be getting worse had ceased completely and seemed to be s
1	of the de getting worse had ceased company well on the way to
2-	of the coloscomy ting worse had ceased completely while seemed to be getting worse had ceased completely while condition that I'd had for even longer was well on the way to condition that I'd had for even longer was well on the way to
5-	condition that I'd had for even longer was well on the disappearing with my hair getting back to how it was more than
(m)	
-	effective in helping
	None of the usual medication had been very effective most me with any of these issues but I am generally, like most me with any of these issues but I am generally, like most
	me with any of the first in remote places where western people who have lived in remote places where western is unobtainable, a big fan of allopathic medicine and rather is unobtainable, a big fan of allopathic medicine and rather my
	people who have a big fan of allopathic meature tink between my
	people who have the fan of allopathic medicine and is unobtainable, a big fan of allopathic medicine and my on the sceptical side about alternatives. This link between my on the sceptical side about alternatives and hot proven
	is unobtainable, a try, on the sceptical side about alternatives. This link between improvement and kefir is obviously anecdotal and not proven improvement and kefir is obviously anecdotal and not proven improvement and kefir is obviously anecdotal and not proven
	on the sceptical state is obviously anecdotal and not p improvement and kefir is obviously anecdotal and not p but it has been so dramatic that perhaps research about it shoul but it has been so dramatic that perhaps research about it shoul but it has been so dramatic that perhaps research about it shoul but it has been so dramatic that perhaps research about it shoul but it has been so dramatic that perhaps research about it shoul but it has been so dramatic that perhaps research about it shoul but it has been so dramatic that perhaps research about it shoul but it has been so dramatic that perhaps research about it shoul but it has been so dramatic that perhaps research about it shoul but it has been so dramatic that perhaps research about it shoul but it has been so dramatic that perhaps research about it shoul but it has been so dramatic that perhaps research about it shoul but it has been so dramatic that perhaps research about it shoul but it has been so dramatic that perhaps research about it shoul but it has been so dramatic that perhaps research about it shoul but it has been so dramatic that perhaps research about it shoul but it has been so dramatic that perhaps research about it shoul but it has been so dramatic that perhaps research about it shoul but it has been so dramatic that perhaps research about it shoul but it has been so dramatic that perhaps research about the shoul but it has been so dramatic that perhaps research about the shoul but it has been so dramatic that perhaps research about the shoul but it has been so dramatic that perhaps research about the shoul but it has been so dramatic that perhaps research about the shoul but it has been so dramatic that perhaps research about the shoul but it has been so dramatic that perhaps research about the shoul but it has been so dramatic that perhaps research about the shoul but it has been so dramatic that perhaps research about the shoul but it has been so dramatic that perhaps research about the shoul the shoul the shoul the shoul the shoul
	improvement and RCA but it has been so dramatic that perhaps research about the but it has been so dramatic that perhaps research about the be undertaken. Incidentally, in case it is relevant, I am 83 year be undertaken. Incidentally, in case it is relevant, I am 83 year old, and still as active as ever, both physically and mentally.
	be undertill as active as ever, both physically a
	ola, una seconda de la
	Claudia

What is Kefir and is it safe for ostomates? Sophie Medlin Dietitian



Kefir is a fermented milk drink which contains friendly bacteria or 'probiotics', which has become popular in the last few years. It is a bit like yogurt in taste, it contains many of the same bacteria as live yogurt and is sometimes slightly fizzy.

Kefir is produced by adding a starter culture of bacteria to milk. The starter culture is called "kefir grains" and they contain lactose fermenting yeasts and other yeasts as well as bacteria that are known to have positive effects on the body if they populate the colon effectively.

There is a lot of variation in kefir because its manufacture is not fully regulated. Many people also make kefir in their home using kefir grains which have been bought online which also increase the variability in the bacterial profile and therefore the benefits experienced.

What does the research say?

There is some limited evidence from scientific research to show that kefir can colonise the colon and that when they do, they have positive effects in boosting the populations of good bacteria and lowering the populations of less favourable bacteria. When we talk about our colonic bacteria, it is always important to remember that everyone has a completely different microbiome (the balance of bacteria and colonic environment that they reside in). So different, in fact, that it is as unique as our finger prints. This means that everyone responds to probiotics like kefir differently. Add to that, that two kefirs are never the same and you can see why everyone has a different experience when they take it and why the science is so conflicted.

Should I try Kefir?

As a starting point, it is important to remember that people with an ileostomy, don't have a colon at all and so when we look at the colonic bacteria that are supported by kefir in the research, this isn't relevant for people with ileostomies.

That said, If you do have an ileostomy or a colostomy and you've cut out milk due to tolerance issues, you may well be able to tolerate kefir as the lactose which is typically the irritant in dairy has been fermented by the yeasts and bacteria before you drink it. This may allow you to reintroduce dairy and benefit from the nutrients it contains.

There is some evidence that kefir might improve stool weight and moisture content, which might support patients with a colostomy, who suffer from constipation or pancaking to overcome this. This is likely (although it hasn't been studied) to cause more problems for people with an ileostomy.

There are a few people who should avoid kefir such as those on immunosuppressant therapy for inflammatory bowel disease and those undertaking chemotherapy. If you're not sure if this applies to you, please talk to your doctor before trying any probiotics.

We need to remember that there isn't the evidence to recommend kefir to the general population or people living with irritable bowel syndrome type symptoms at the moment, let alone to recommend it to people who have had any sort of bowel surgery.

While the risks for most people with a stoma are low, the benefits are likely to be highly variable for each person. People with a colostomy are far more likely to benefit than those with an ileostomy but as usual, a trial and error approach is advised.

If you want to try kefir, try a small amount to start with and always buy from a reputable brand.

Living with the 'Creature' Jenny Hill





After a few years of suffering with endometriosis and having almost yearly laparoscopies to remove cysts from my ovaries, I decided to have a full hysterectomy. The surgery took place on 31 January 2018 and seemed to go well. There was a slight hiccup two days afterwards when my temperature spiked and I had to go on intravenous antibiotics, but at the time this didn't seem particularly significant. All I remember is that I was sick the day after and so was kept in an extra day because I couldn't eat anything. Little did I know that 10 months later, my surgeon would be telling me that stoma surgery was the only solution to my problems and that this needed to be done the very next day.

After being discharged following my hysterectomy, things didn't really improve and I alternated between being sick and explosive diarrhoea. Having never had major surgery, I thought this was par for the course. But after three weeks of it, my partner Garry took me back to hospital (even though I was adamant I was fine!). At this point things started to get scary. I still remember the awful feeling I had when I heard them saying I would need a blood transfusion and the problems that followed as they tried to get the cannula in for what turned out to be three units of blood.

I was then put under the care of a gastroenterologist, who at first thought I had clostridium difficile (more commonly known as C-Diff). For those that don't know, this is bacteria that can infect the bowel and cause diarrhoea. It is something that commonly affects people who have recently been treated with antibiotics. The tests, however, all came back clear. Next I had a CT scan. This revealed that I had ulcerative colitis, which at the time was something I knew nothing about.

Then came the huge learning curve of living with a lifelong condition. I spent the next three weeks in hospital doing little else but talking about poop and learning about the Bristol Stool chart. Having never been one to talk about my toilet habits, I found this really hard at first. Eventually though, I got over the embarrassment of talking about my movements. I was also started on a biological drug and things started to get back to normal. When I eventually went for a follow–up appointment some nine weeks on from my hysterectomy, I learned from the surgeon that he had had problems 'un-sticking' my uterus from my bowel due to the endometriosis.

Sadly, my story didn't end with this meeting. Shortly afterwards I developed a perianal abscess which, as well as being terribly painful, was also very embarrassing. The abscess kept getting infected. This meant antibiotics, but these seemed to trigger a flare–up with my ulcerative colitis. This in turn made the abscess worse, meaning it had to be drained. I was caught in a vicious circle. This happened three more times over the next three or four months. I was in constant discomfort and seemed to forever be going back and forth to my (amazing) surgeon regarding it.

This was clearly a situation that couldn't go on indefinitely. It was now November 2018 and despite all the treatment my abscess was showing no signs of going away. It was at this point my surgeon told me the news: the only solution was a temporary colostomy to let everything heal. Surgery was scheduled for the day after.



This gave me no time to prepare or properly understand what a colostomy was, what a colostomy bag looked like and how the whole stoma thing worked. I still don't know if this was a good thing (as I had less time to get frightened) or a bad thing (as I had no time to prepare). I spent the next 24 hours in a blur of pain and pain relief, unable to focus and think clearly. I did a lot of crying and kept asking myself, how did I get here? A year ago, I was healthy and had never had an overnight stay in hospital and yet here I was now with a lifelong condition and having to have a bag!

On the day of the surgery, my surgeon measured me up. As it was a Sunday there were no stoma care nurses available to do this. He admitted that he had never done this, but luckily managed to avoid the need to cut through my lizard tattoo, who now 'holds' my stoma. The worse thing I can remember about those first couple of days after the surgery was having the nurses empty my bag. I've never felt so embarrassed. Like many people in that immediate post-op period I refused to accept or even look at the bag. Thankfully I had amazing support from family, friends and my stoma nurse. Not once did they push me to look at or change my bag, until it got nearer to discharge day. It must have taken a good 20-30 minutes, but I did it and felt so proud!

Fast forward to now and I've been 'upgraded' to Crohn's, as well as perianal disease, a prolapsed Stoma, constant infections, and fistulas. But, if it wasn't for the 'Creature' (pet name for my stoma) I'm not really sure where I'd be. Instead, I'm still here, I'm still learning, and I'm actually liking the creature. He might cause me problems but nothing like I had a year ago. I'm now back to nearly 'normal' working order, back to work, back to enjoying supporting my partner in his mountain bike racing. I've even changed my bag in the back of a transit van in a field while a race was going on about me! One thing I do know for sure, is I'm not ashamed of having this disease or having a stoma. Everyone I work with knows about it, including the board of directors!

The next big decision I face, is whether or not to go for a reversal. As things stand, I'm perhaps 75–80% thinking that I will keep the Creature, mainly because with a reversal there is no guarantee that I won't encounter the same problems I had before.

As you have probably worked out, throughout most of 2018 I was in a very low place – both mentally and physically – and don't want to go there again. Thankfully, this time I have more than 24–hours to decide.

	Supporting and	
	Stoma Reve	Colostomy
	www.ColostomyUK.org	
you 🥢	15	
ing 🗾 📝	Stoma helptine:	2.5
a 🗾	0800 328 4257	24/7
al?		
then	and the second s	

remember, **Colostomy UK** have volunteers who have had reversal surgery and would be happy to share their experiences with you. Call our stoma helpline on: **0800 328 4257**, to arrange.

Are

think

about

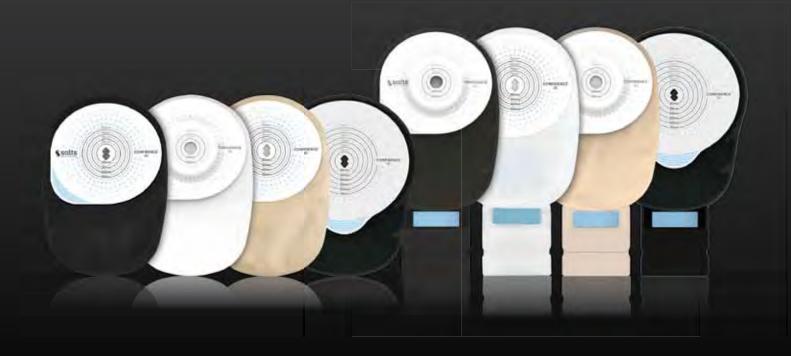
reversa

If so,

We also produce a booklet on *Stoma Reversal.* You can download it free from our website. Alternatively call us: **0118 939 1537** or e-mail: **info@ ColostomyUK.org** to request a copy.

Order Form Colostomy	Irrigation and You (Patients)	Colostomy Irrig. and You
Colostomy UK to raise awareness ab Note: Not all colostomates can irrigate. It surgeon/stoma care nurse as they will ad To obtain your single copy of <i>Colosto</i> postage and packing) simply fill in yo payable to Colostomy UK , to: Colostomy UK , Enterprise House, 99 itle:	educational DVD aimed at patients, it has been produce bout <i>colostomy Irrigation</i> as a method of bowel mana- is therefore essential in the first instance to consult your vise as to your suitability. <i>The product of the second price of for the se</i>	An educational DVD Composition of all and the second secon
lame: \ddress:		
	Postcode:	
el:		
mail:		
Please allow 30 days for delivery.		





BE IS FOR BIGGER SIZES

LARGE WAFER BAGS ARE NOW AVAILABLE!

CONFIDENCE BE[®] already comes with a range of innovative features, for extra confidence, flexibility and comfort. Now, we've introduced flat wafers which can be **cut up to 75mm**, offering a bigger adhesive area, for added security. Which means people with larger stomas can

For samples or more information: Freephone **0800 028 2144** (UK); email **samples@salts.co.uk** or visit **www.salts.co.uk SaltsHealthcare** SaltsHealthcare

Salts HEALTHCARE





® Registered trademark of Salts Healthcare Ltd. group 2019. Reference code: MA269

enjoy all the great benefits too. The new bags are available in closed or drainable, in the same three colours as our original design.

CONFIDENCE BE[®] For all you want to be



SUPPORT

Your letters and e-mails

Ed's note: Since the last edition of *Tidings* I have continued to receive letters about prescriptions and the new formularies. Thank you to everyone who has sent these, it's a situation that Colostomy UK is monitoring closely. Rather than publish more of the same, I have picked a couple of fresh topics from our mailbag.

Dear Sir/Madam

For many years I have been receiving various "cures" for severe pain in the stomach area. I have been prescribed different types of antibiotics, put through different regimes of diets. One was a liquid diet that did nothing to ease my severe stomach pains but left me very tired and lethargic. I was even advised to buy over the counter pain relievers.

Then I happened to talk to someone who had diverticulitis. So, I read up everything I could about diverticulitis. I understand that diverticula are small pouches in the lining of the digestive system mostly in the large intestine. These can become infected and inflamed. I approached my doctor to discuss the symptoms with an idea that this particular diagnosis (albeit mine) could be investigated. I was assured that a diagnosis of diverticulitis would have shown up in bouts of nausea, fever and a change in bowel habits and because I am over 40 and because I had shown none of these symptoms this would not be the case.

At my insistence he referred me for a scan and once the results were back it was seen that I had many pockets of diverticula that were inflamed and infected so causing this dreadful pain.

I have been told I can have an operation to remove the infected pockets. It has been explained to me that the infected area will be removed, but it might mean me having a temporary colostomy to allow the bowel to heal. I am really concerned about this. I do not like the idea of having a bag even though I am told that it will be temporary. The thought that it might affect my lifestyle and my plans for the future is holding me back from making the decision to go ahead with the operation. I was passed your magazine and after reading it I have plenty of knowledge about a colostomy – and while I am full of admiration for your members who write about their challenges and how they now have normal lives, I am still reluctant to take that step. Do you have any readers that can reassure me that the pain will be taken away, the recovery time from the operation will be short and that my life without pain will be given back to me?

I would be grateful if someone who has suffered as I have would answer and tell me the whole unvarnished truth about this matter.

Linda B

Ed's note: Readers will be pleased to hear that since writing, Linda has spoken with one of **Colostomy UK's** volunteers who was able to chat through her concerns.

Dear Editor

Thank you for another interesting autumn edition of *Tidings*. I am also a follower of your website and find the articles and advice extremely helpful.

I would like to ask if you can help me know how to choose the correct support garment to help me from getting a hernia.

I have read several articles about how important it is to have such a garment but I am really struggling to know what type I should ask for.

I know there are support belts. They seem to come in two widths and I can have the length adjusted to fit my waist measurements...small, medium or large. What I don't understand is – if I place it round my waist area to cover my stoma it does not support me from the bottom, where I would suspect the hernia forms. Or am I wrong?

So how do I get that 'liff' to stop my tummy area from 'dropping' I note that I can have the belt with a pre-cut hole especially for my pouch. This means that I do not have the problem of a tight fitting belt putting pressure on my stoma therefore flattening my pouch which would lead to pancaking. I have read that these support belts are very important when you returning to normal tasks of lifting or stretching such as gardening.

I have also studied the information on support panties (I am a woman). These give good and full support but again with such a choice which one do I chose? You can have pants with or without an internal pocket that will hold your pouch. These too are available in small, medium or large. Or, you can choose to have a tight fitting full support girdle.

I have discussed this with my stoma care nurse who assures me that I can choose any of the support garments that are available. I also know that she will refer me to a company that can measure me for the correct size. BUT how do I find out and/or try out the actual support garment that will suit me?

CONTINUED ON PAGE 19, COLUMN 1

Please note:

Before acting on suggestions from other ostomates regarding medication or treatment you must check with your doctor or stoma care nurse that this course of action is suitable for you.

Ultra ~ Frame

can you see it?

Ultra-thin - Ultra-transparent - Ultra-discreet UltraFrame®

The thinnest film flange extender in the world



For a free sample of UltraFrame®, please complete the coupon and return it to: CliniMed Ltd., Freepost RTJG-ZZCJ-JAYS, CliniMed, Industrial Estate, Knaves Beech Way, Loudwater, High Wycombe, HP10 9QY (NO STAMP REQUIRED), call our free confidential careline 0808 149 2722 or visit www.clinimed.co.uk

Mr/Mrs/Ms:	Initials:	Surname:	Address:	
			Postcode:	
Tel No:		E-mail:		

When you return this form to us, we will use the details you have submitted in order to process your request. We and our sister company (SecuriCare) would like to contact you occasionally about relevant products and services. Please will you confirm your agreement to your details (including the health information you have given us), being kept on file and to being contacted in the following ways (please tick to confirm consent): Post Telephone Email NB: you can unsubscribe from our mailing lists at any time by clicking the opt-out link in any of our emails, calling Freephone 0800 036 0100 or emailing info@clinimed.co.uk. Our privacy policy can be found on our website www.clinimed.co.uk or call 0800 036 0100.

Manufactured by Wellend® a Clinimed® Group Company. Welland products are distributed in the UK by Clinimed Id. Tel: 01628 523579 Email: enquiries@clinimed.co.uk or visit: clinimed.co.uk Clinimed Id., a company registered in England number 01646927 Registered office: Cavell House Knaves Beech Way, Loudwater, High Wycombe, Bucks HP10 9QY. Clinimed®. Wellend® and Ultraframe® are registered trademarks of Clinimed (Holdings)

SUPPORT

CONTINUED FROM PAGE 17 COLUMN 3

I know that a support garment may be obtained on my prescription but I am reluctant to order such an expensive garment without being sure it is what I need. With today's restrictions on prescription items and because of the cost, I am even more aware that I have to choose the correct garment.

I would appreciate hearing how other people decided on the correct support garment for them and how they feel about it some months later.

Ruby Y

Ed's note: Hopefully Ruby will find Lisa Tate's article on page 35 useful.





We look forward to hearing from you,

our readers:

Send an e-mail to: info@ColostomyUK.org

Write a letter to:

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

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

Silex,

"Silex"

Turn your frown upside down

Don't stick with what you've always stuck to

Ultra-thin Trio Silex[®] is a breathable silicone flange extender designed to provide extra security and protect the edges of the flange leading to increased wear time.

Order your FREE sample at www.TrioOstomyCare.com

SUPPORT A huge thank

Julie Rust, Clinical Nurse Specialist at University Hospitals of North Midlands NHS Trust, retires after a nursing career spanning 37 years.

Julie has been involved with our charity since the days when we were known as the British Colostomy Association. In 2004 she agreed to answer readers' questions in *Tidings* and continued to do so in every issue for the following fourteen years.

From an early age, Julie always wanted to become a nurse. Her family had links with the local hospital: her dad was an "ambulance man" and her mother worked in "casualty". In 1982 she began her training as a nurse at the Royal Infirmary, Stoke–on–Trent, and qualified three years later. Her first position was on a general surgical ward where some patients were undergoing colorectal surgery and this is how she first became interested in stoma care. She specialised in colorectal and stoma care in 1990 and became a clinical nurse specialist in 1998.

Ernie Hulme, volunteer and vice chairman of the board of trustees of British Colostomy Association/Colostomy Association/ **Colostomy UK** for many years, was one of Julie's first patients. He told her how helpful he found it speaking to another patient who already had a stoma, and Julie mentioned this to her boss, Val Moss. Julie explains how, as a result, in 1999 she, Val and Ernie set up the North Staffs Ostomy Support Group, 'Outlook':

"We had an inaugural meeting where we invited patients to see what the interest would be like to provide a support group. The idea was to get a group together that would provide visitors to new ostomy patients in the hospital. From there we developed a core group of different ages, sexes and with different types of stomas so we could match the appropriate visitor with new ostomy patients and this still is continuing today."

In the Summer 2007 issue of *Tidings*, Julie wrote about her working day at the busy Bowel Care Department of the University Hospital, North Staffordshire: visiting inpatients in the morning, running a nurse–led clinic in the afternoon, and fitting in answering phone calls, home visits and all the other tasks, expected of a stoma care nurse in a busy acute hospital.

Julie also wrote about how she and her husband, Steve, a community paramedic officer with the Staffordshire Ambulance Service, juggled full time jobs and care for their two daughters Megan then aged nine and Caitlin aged seven as well as two Staffordshire bull terriers, Reggie and Roni.

It was way back in December 2004 that Julie took over the *Tidings* Dear Nurse page; she answered readers' questions on stoma care for the next 14 years. Julie says:

"I can't believe that I have been doing it for so long. I remember being asked to do it and was told it would be a 'one off'. Then I was told that it would be done on a rota basis sharing the role with nurses from other parts of the country. Well that didn't occur... and I've ended up doing them all. To be honest, it's been quite a privilege to have been asked and to have been able to answer so many questions for people around the country."

As editor of *Tidings*, I always knew I could rely on Julie to come up with practical answers to unusual stoma management

SUPPORT



Introducing... Julie Rust, Clinical Nurse Specialist in Stoma Care at the University Hospital of North Staffordshire

> Julie Rust being introduced to Tidings readership, December 2004

problems. If our readers needed specific medical advice, she would always refer them back to their nurse or consultant. Her answers always arrived in time for the magazine's deadline.

In July 2015 at a gala dinner, Ian Daniels MB ChB, FRCS (Eng), president of the Colostomy Association, presented Julie with an award to acknowledge the huge impact her work had had, not only on *Tidings* magazine but also on the lives of thousands of people. Julie remembers this day well and says:

"The vase I was given sits at home and is periodically filled with flowers by my husband".

Today we don't receive as many letters for the Dear Nurse page as we used to. Julie reflects on why this has happened:

> "It's changed over the years. Patients now have the access to the internet and the ability to get answers to their questions immediately." But she reminds us: "Even with this ability to get some answers there is always a place for asking a specialist nurse their opinion."

Julie has always worked at the same hospital, although its name has changed over the years and it has now become part of a large trust under the title University Hospital of North Midlands (UHNM). Julie says:

> "In all I will have done 37 years when I retire! It's a nice feeling knowing I started and finished here and I have served the people of Stoke (my people) my entire career."

I ask Julie whether her children have followed the family tradition of working in the NHS. She replies:

> "Neither have followed me or Steve into the medical profession. The closest is Meg as she is studying Forensic Science. She's just started her third year and wants to go on to do a Masters when she's finished. Cait is now in her second year reading History and is looking at going to the USA to study for her third year. She wants to do a Masters in Journalism when she graduates."

Now that the children have left home and her husband is still working full time for West Midlands Ambulance Service as an Operations Manager, I ask Julie how she will fill her days. She reassures me that won't be a problem:

> "Whilst I am retiring from full time work, UHNM have persuaded me to return part time to continue doing cancer follow–up clinics, but only two days a week! I always said I like to work the weekends and have the week off and now I can!"

And how will she be spending her free time? Julie says:

"We have a motorhome and we go away a fair amount now but



Julie Rust receiving her award from Ian Daniels, Colostomy UK President, at the 2015 Gala Dinner

from November we'll be away even more. We both like walking, eating out and visiting new places. Steve likes bird watching and I'd like to give painting a go, particularly landscapes in water colours, so we can relax together in the countryside. I also want to do some genealogy and trace my family origins."

Thank you, Julie. We really appreciate your support and valuable contribution to *Tidings* over the years, first to the British Colostomy Association, then the Colostomy Association and more recently **Colostomy UK**.

> Rosemary Brierley Volunteer and past editor of *Tidings*



Irrigation and you



The basics

Ambra Bertinara Stoma Care Nurse Specialist NUH NHS Trust Nottingham

Since becoming a stoma care nurse, I have developed an interest in using irrigation as an alternative way of managing a colostomy. As the benefits of colostomy irrigation are not widely acknowledged in the ostomate community, I have put together some useful answers to common questions on this topic.

What is colostomy irrigation?

One of the first mentions of irrigation is in 1793, when an 'artificial anus' was formed in an infant with a bowel obstruction and water mixed with drops of rhubarb syrup was introduced to cleanse the bowel¹. Yet, despite this seemingly long history, colostomy irrigation is still not widely used. Rather than using a pouch to collect the contents of the bowel, irrigation gives the ability to take control. The aim of this procedure is for the bowel to be stimulated to contract (peristaltic action) and then to expel the contents of the last part of the colon. It involves the instillation of 500ml up to 1,500ml of warm tap water into the colon via the stoma to wash out faecal matter. Irrigation is generally carried out daily or every two to three days and results in little or no stool evacuation from the stoma until the next irrigation.

When colostomy irrigation can be taught?

Colostomy irrigation can be taught as little as three months after surgery or years after surgery, however individual circumstances will always be assessed, such as healing of the surgical wound or general postoperative recovery. The colorectal consultant's approval must be obtained before any teaching is started and the general practitioner (GP) will be notified.

Can anybody irrigate?

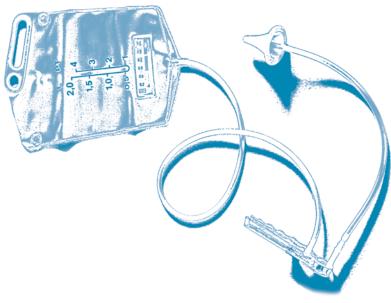
An assessment is carried out by the stoma care nurse, who will gather important medical data and underlying conditions to check suitability for irrigation.

Colostomy irrigation is **NOT** appropriate if you:

- Have a colostomy on the right hand side or a transverse colostomy as the motion is likely to be too fluid.
- Have any active inflammatory bowel disease (ulcerative colitis or Crohn's disease) as regular stimulation and contraction of the bowel may cause a flare up of the disease or fistulae formation.
- Suffer from irritable bowel syndrome as the procedure may cause abdominal pain and spasms.
- Suffer from diverticular disease or if you are prone to diarrhoea, as the procedure may not be successful.
- Have heart or kidney disease as there as there is a potential for complications caused by fluid absorption and "overload".
- Have stoma complications such as a symptomatic parastomal hernia, colostomy prolapse or colostomy tightness (called stenosis); these may make irrigation too difficult.
- Have a fistula, radiation damage, existing colorectal cancer or metastatic disease.
- Are having chemotherapy or radiotherapy treatment.
- Have poor eyesight or manual dexterity as it can be difficult to manage the equipment.

Do you irrigate? If not, are you interested in trying? If you would like to try irrigation you should first contact your stoma nurse to see if you are a suitable candidate. If you get the go ahead they will arrange a time to teach you. For more information see the **Colostomy UK** website or purchase the Irrigation and you DVD using the form on page 15.

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



What are the advantages of colostomy irrigation?

With successful irrigation, it may be possible to gain continence and control over the stoma which can minimize or completely prevent odour and wind production. In addition, it may reduce or prevent problems related to your pouch, such as leaks or allergic reaction. As the output after irrigation is low, a cap or mini–pouch can be used to protect the stoma, making the colostomy less visible through clothing. Also, the equipment will last a considerable time and is more compact than the bulky supplies of appliances. Many ostomates report a better quality of life, with improvements in their working lives and social activities².

What are the disadvantages of colostomy irrigation

The most commonly reported disadvantage of irrigation is related to the time involved in completing the procedure; generally it takes around 45 minutes to one hour. Some people may find it difficult to free up this amount of uninterrupted time, making it challenging to form a regular routine. Sometimes, irrigation can make you feel sick or faint, but this usually settles quickly and is less likely to happen as your body becomes used to you irrigating. There is also a very slight risk is of perforating the colon if an inappropriate technique is used.

What to expect from the teaching sessions?

Prior to attending the colostomy irrigation clinic your stoma care nurse may offer you various information sources such as booklets, videos, or photographs and can show you the equipment that is used. Sometimes, speaking to someone who already irrigates can be helpful and, where possible, an opportunity for you to do this will be provided.

Remember this is something you can arrange through **Colostomy UK.** Many of our volunteers are 'irrigators' and would be pleased to talk to you about their experiences of irrigating and impart some top tips. They will also tell you that in the early days perseverance is very important!

The number of teaching sessions will be tailored to meet your needs and may vary from a minimum of one to a maximum of five sessions. On the first day, the stoma care nurse will demonstrate how to irrigate. It is often a stop and start process due to loaded bowel. You will be encouraged to have a go at holding the cone in place and regulating the water flow. Remember to drink plenty of fluids prior to coming to the teaching session to avoid a poor result as if you are dehydrated, the bowel will naturally absorb more of the water. On the second day, you may be encouraged to put the cone in place and do the procedure by yourself, with the stoma care nurse guiding and supporting you as necessary. Following the teaching sessions, once you and your stoma care nurse are happy that you can manage, it is advisable to irrigate every day at a similar time for approximately six weeks and to wear your usual pouch, until a routine has been established. After this time, it may be possible to irrigate less often, perhaps every 36-48 hours, but this varies from person-to-person. It is good to remember that initially some days may be better than others, but this should not be a cause for worry – don't panic and try again the next day.

'O'Bichere A, Sibbons P, Doré C, Green C, Phillips R K, (2000) Experimental study of faecal continence and colostomy irrigation, *British Journal of Surgery*, 87, 902-908, p. 902.

²Grant M, McMullen C, Altschuler A, Hornbrook M, Herrinton L, Wendel C, Baldwin C, Krouse R (2012) Irrigation practices in long-term survivors of colorectal cancer with colostomies, *Clinical Journal of Oncology Nursing* **16**, 514-519.

"I can bend with confidence"

Neil, SenSura® Mio Convex user



The better the fit, the lower the risk of leakage

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

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





With BodyFit Technology®

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

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

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

Request your FREE sample

First name	Surname
Date of birth	Email
Date of Stoma Surgery	Telephone No.
Signature	How your information will be used - By providing your personal and sensitive personal data on this form, you are consenting to Coloplast Charter using it for administration and analysis purposes and to process your order. We may share this information with healthcare professionals and other companies required for the delivery of your products or as required by law. We may also contact you to ask you to clarify your requirements and to ask you to complete customer satisfaction or other surveys, and may use 3rd parties to handle this as outlined in our Privacy Policy which can be found at Coloplast.co.uk/privacy. We often keep customers up to date with the latest information on the products and services we offer. Please indicate if you would not like to be keet informed by:

Email SMS Phone Post



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

New products

and services

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

NEW! UltraFrame® **Ultra ~ Frame**



The thinnest flange extender in the world, UltraFrame is a revolutionary flange extender designed to keep your bag securely in place. UltraFrame is made from an ultrathin, transparent and waterproof film, making it ideal for bathing, swimming and sports.

Available on prescription.

Visit www.clinimed.co.uk, call 0800 036 0100 or email info@ clinimed.co.uk for a free sample. To see how three rugby league players found using UltraFrame head to www.clinimed. co.uk/ultraframe-rugby-video

See our main advert on page 18.

NEW Confidence BE[®] Large Wafer

CONFIDENCE BE®

For all you want to be

Our popular Confidence BE[®] bags are now available in a larger wafer size that cuts up to 75mm, giving a bigger adhesive area for even more security. The new Confidence BE[®] Large Wafer bags are available in closed and drainable, and contain the same range of clever features and colour choices as our original design.

For samples or more information: 0800 028 2144 (UK) 1-800 408508 (Ireland) www.salts.co.uk



Colostomy

Brava® Belt for SenSura® Mio



At Coloplast we are committed to listening and responding to the needs of our customers. We therefore have redesigned the fastening hooks on the Brava Belt to include:

- Longer hook length designed for better attachment
- More pointy hooks which have been moved forward – designed for increased ease of application.

For more information visit www.coloplast.co.uk/brava-belt See our main advert on page 24. OSTOMATES DESERVE A LIFE LIKE EVERVONE ELSE.

Donate to help us support and empower.

www.ColostomyUK.org/donate 0118 939 1537

Listen out for Colin from Cheltenham on Radio 5

Colin Williams

In January 2009 I celebrated my 60th birthday. As well as receiving a variety of gifts, I got a postal invitation to take part in the bowel cancer screening programme. My health at the time seemed good. I was enjoying active participation in golf and many other things, so I was shocked to be informed that my first test had thrown up a problem. I was invited to try again. To cut a long story short, this quickly led to an appointment for a colonoscopy. Several polyps were removed and subsequent tests and scans revealed serious bowel cancer. Over the next two years, after two major operations and periods of radiotherapy and chemotherapy, I was left with a permanent stoma.

Sometime afterwards I discovered irrigation. For years, I read a book or the paper while irrigating. As readers who irrigate will know, the whole procedure can take up to an hour to complete, so this proved a good distraction. Indeed, it was so good a distraction, I have to admit that I often spent more time in the bathroom than was really necessary. My wife would often wonder if I was ever going to emerge. In order to free–up the bathroom and maintain marital harmony, I decided to give up reading in favour of listening to the radio. My thinking was that with radio shows having a definite start and end time, it would help me to avoid overstays!

Being an avid sports fan I was already a frequent listener of Radio 5. But tuning in at irrigation time meant I quickly became hooked on the breakfast show. The banter between Rachel Burden and Nicky Campbell is particularly enjoyable. Like the other presenters, they also do their best to involve the audience by inviting listeners to text in views and opinions on topical issues. They also encourage humorous comments and anecdotes. And so began my radio career...a career that has developed while irrigating! I would listen and I would text, and it wasn't long before I found that I was quite successful at getting on the 'air'. It gave me a welcome lift to what was otherwise a potentially tedious hour in the loo.

One of my first texts was read out on a Saturday morning by Chris Warburton. He had just interviewed a listener who had explained how she regularly wrote to companies expressing her love of their products in the hope of receiving vouchers and free gifts. By all accounts this had proved a highly successful ploy. I seized the moment and texted in the following:

I really love your programme, Radio 5 and the BBC. Any chance of some vouchers to help pay for my TV licence?

Receiving this text so soon after the feature clearly amused the show's presenters. When Chris read out my text, he rather hesitantly said he would see what he could do. I haven't heard back from him yet and, as it's been a few years now, I'm not holding out much hope!

Although I'm still having to pay for my TV licence, this brief moment of stardom proved all the incentive I needed to send more (and more) texts. Without counting, I guess my success rate to be around 40 texts read out. In fact now, when they aren't read out, I get a little disappointed. I've contributed my thoughts on a wide range of subjects and always try to include a tinge of humour. Even during the dark times of my illness, I was determined to see the funny side of most situations and it has helped to keep me sane. On the whole, I have tried to avoid saying anything about Brexit (other than the odd short sarcastic remark). I work on the basis that most listeners, like me, are probably sick to death of the whole thing!

Some of my texts are listed below. I hope you find some of them amusing:

Film accuracy – We watched 'Eddie the Eagle' at our local film society in Cheltenham. Before it began, there was an interview with Eddie who claimed the film, though very enjoyable, was about 5% accurate.

CONTINUED ON PAGE 29, COLUMN 1

REAL LIVE



F Looking for online support?

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

Search for **Colostomy UK support group** on Facebook and request to join. *We look forward to welcoming you.*

www.ColostomyUK.org

Stoma helpline:

0800 328 4257



CONTINUED FROM PAGE 27 COLUMN 2

Job I'd like someone else to do for me – Defrost the car on a frosty morning. (Not by running the engine).

Number plate cloning – I had a speeding summons in the post from the Metropolitan Police two years ago. Fortunately I had photographic evidence that I was in South Wales on the day of the offence. I eventually received an apology as it turned out not even to be my make of car.

Sport Improvisation – I took my primary school football team to another local school and on arrival was confronted by their rugby team. To compensate for the mix up we played 20 minutes of football the another of rugby. We won both.

Meeting the in-laws for the first time - I was invited for a weekend. During the first evening we watched University Challenge and I quickly realised that I'd seen the programme previously at home on a different regional channel. Without making it too obvious, I slipped in an impressive number of answers to the questions. My wife and I have been married for 45 years.

Worst interview experience - Minutes before being interviewed for a deputy headship I discovered that the internal candidate gave the head teacher a lift to school everyday.

Experiences – For my 70th birthday one of my son's gave me a steam train driving experience on the Gloucestershire-Warwickshire Railway. I was really chuffed.

Nicknames – My son had a friend at university who had the nickname 'Olympic Flame' because he never went out.



My radio career hasn't stopped at texts. In fact that first text was the start of something bigger. Since my early steps into the world of media stardom I have been phoned back numerous times by researchers and have gone on to make a number of telephone appearances live on air. My past profession has been a great help with these. Before I retired, I was the head teacher of a large primary school in Cheltenham. As you can probably imagine, this has given me an array of experiences and stories to draw upon. Many of these are comical, making them ideal material for a breakfast radio show. So far I have chalked up (if you will excuse the teacher pun!) six 'live' appearances. I have talked about one parent's behaviour at a school football match, my memories of taking the children on school trips and how I once gave a famous person a lift. I've shared my views on Ben Stokes winning a test match almost single-handedly. I have also made contributions on more serious subjects such as cancer, the Big C.

Now, when my mobile rings displaying a private number, I know what to expect. Although despite my fame I still get my fair share of unwanted calls about accidents I've apparently been in! Sadly, at the time of writing I am experiencing a down period with two of my recent texts being rejected. Paul McCartney has apparently written a children's book Hey Grandude and the presenters asked listeners to submit other titles that he may have written. Rather surprisingly, my efforts, which attempted to incorporate the titles from Beatles' songs and included Please Mister Postman Pat and Fixing a Hole and Other DIY Projects didn't make the grade. So, I think I am going to have to diversify if I am to remain in the limelight; or 're-invent myself' as us media types say. Perhaps I could start writing jokes for Christmas crackers!

Disability Rights UK

r has a med

n and needs urgent acce

The cardhold

disabled facil

Date:

All the best **Colin Williams**

123e45

Non - thank y

ed line and return to the address on this form

1 top

the

4

T56

Photo ID Card

п

lovember 2019 | Copyright ©2018–2019 Colostomy UK | Registered charity no. 1113471

I

I.

Date

hoto ID Application

н

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

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

• A copy of your prescription or delivery note as proof of eligibility

Passport photo x 1

Payment – cheque or credit card*

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

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

Allow maximum of 10-14 days for delivery.

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

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

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

National Key Scheme – Key and photo ID card purchase

Title:	Please tick as appropriate:
Name: Address: Postcode: Tel:	 I would like to receive a key £3.50 (including postage and packing). I would like to receive a photo ID card for £6.50 (including postage and packing) and enclose a passport photograph. NOTE: Please send a copy of your prescription/recent delivery note as proof of eligibility and make the cheque payable to:
Email: DECLARATION: I declare that the individual named above is chronically sick, has a disabling condition or has had a bowel or bladder diversion that necessitates the use of accessible toilet facilities. The key is for the personal use of the above named and their designated carer only.	Colostomy UK. For payment by credit card, send your documents in the post with a contact telephone number, we will then call you to take a card payment when received.

Signature of self or carer:

Colostomy UK: active ostomates[®]



Giovanni Cinque Fundraising and Development Manager **E:** Giovanni.Cinque@ColostomyUK.org Welcome to the regular update page dedicated to our 'Active Ostomates' project.

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

2019 in review

It's been a record breaking year for our Active Ostomates project with more activities taking place and in more locations than ever before. Active Ostomates started in 2016 when we launched the first version of our *Sport & Fitness after stoma surgery* booklet and piloted chair yoga with the East Berkshire Ostomy Club.

Chair Yoga



We chose Chair Yoga not just because it is suitable for people of all ages and fitness levels, but also because of its focus on strengthening the core, which is very important for preventing parastomal hernias. Add to this that yoga is a great tool for improving breathing and relaxation techniques...and you can see why we went for it!

It's been great to see how this part of Active Ostomates has developed in the last four years. We've now delivered sessions all over the country. 2019's new locations included Gateshead, Bradford, Nottingham, Gravesend, and York. We also went north of the border for the first time, running a session in Glasgow. Well over 1,200 ostomates have tried chair yoga this year and benefited from the expertise of Debra and Judy our two instructors.

Here are just some of the comments we've received:

"It made me feel so relaxed and I loved the simple movements."

"The breathing exercises really helped with my anxiety."

"Although I used to do yoga for 28 years before my stoma...have not done any since, this is good as I don't have to get onto floor."

"It's surprising how much exercise you can do seated in a chair!"

Swimming



All the evidence will tell you that swimming is one of the best forms of activity that anyone can do. It gives you a full body work out and puts minimal pressure on your muscles and joints. However it is also one of the activities that ostomates worry about the most. Quite understandably, they harbour fears about leakage and worry about their bag coming off in the pool. They are also concerned about the 'public gaze' and generally feel uncomfortable exposing their bag.

By hosting private swimming sessions where the entire pool and changing rooms are open for the use of ostomates and family members only, we have tried to minimise these barriers and encourage people to get back in the pool. There is no organised activity just a chance for people to build their confidence and get comfortable in the water.

We were delighted to host sessions in Derry, Liverpool, Leicester, Windsor and Blackpool this year, an increase on the three swims we ran in 2018.



#ActiveOstomates

Again we had some great feedback from the sessions including these from Liverpool and Windsor:

"I didn't do much swimming at all but I got in the water and that's what matters, smashing the fears with the help of my wonderful family."

"I really enjoyed it. I used to go to aqua aerobics before I had my stoma but haven't felt confident enough since. I'll definitely go back to classes now."

Stoma 66



In 2018 our 50K Challenge encouraged people to get active and helped us to reach (and exceed) a combined target of 50,000 kilometres in a six–month period.

Its success encouraged us to come up with a new initiative for 2019 which aimed to build on the positive impact the 50K Challenge had on hundreds of people. This was Stoma 66.

The idea behind Stoma 66 was based on current research which shows that on average it takes 66 days for a positive habit to form. Our thoughts were that if we could get people active for 66 days, then they would hopefully continue being active once the challenge finished. We also added the little incentive of helping us reach an overall target of 66,000 kilometres. At the time of writing we haven't finalised the figures for Stoma 66 but we're delighted with the impact it has had. Nearly 700 people joined up, an increase of over 90% on last year's 50K Challenge. The range of activities has been similarly impressive. Participants have done everything from swimming and walking, to mountain climbing and Tough Mudder events.

A huge thank you to everyone who has taken part. Look out for the next edition of *Tidings* when we reveal the final totals.

Creative Minds Art



It's really important to keep the mind active as well as the body, that's why Active Ostomates includes getting mentally as well as physically active! Towards the end of 2018 we piloted some 'Creative Minds' art sessions in Wycombe and Bracknell. The idea was for a wider roll out in 2019 if the feedback was positive.

Needless to say, we had some great responses from those early trial sessions and so in 2019 'Creative Minds' was added to our Active Ostomates offering. The sessions aim to empower and enhance the lives of people with a stoma through art and creativity. But we also want people to have a bit of fun! Options that people can try as part of the sessions include Water Colours, Soft Pastel, Acrylics, Decopatch and Papier-mâché.

Over 350 people have taken part in 21 sessions around the UK, including Glasgow, Newcastle, York, Nottingham, and Gravesend.

We're delighted about the relaxed and fun atmosphere that our Creative Minds art project has brought to support groups. Here's just some of the comments we've had:

"Our members really enjoyed themselves. It was a real change from the usual medical tone to the support groups and allowed them to find other things to talk about and be themselves not patients if that makes sense"

"We had so much fun as a group! At the beginning I wasn't sure about it as I can't draw but the instructors really put everyone at ease, and you know what my drawing wasn't too bad!"

If you'd like more information on any of our Active Ostomates activities or would like to get involved in 2020 please contact Giovanni on **0118 939 1537** or send him an e-mail to: **Giovanni.Cinque@ColostomyUK.org**

CONTINUED ON PAGE 33, COLUMN 1

TEAM COLOSTOMY UK TRAINING VEST



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



#ActiveOstomates

CONTINUED FROM PAGE 31 COLUMN 2

Team Colostomy UK Rugby League



Guardian Sport Network The rugby league coach tackling the colostomy bag stigma

Paul Anderson, who won multiple titles after stoma surgery, is telling his story to support a remarkable new rugby league team By Gavin Willacy for No Helmets

Just like swimming and chair yoga, our Rugby League team was started with the aim of getting people active, whether this was playing or coming along to watch the team play. But, something that we have recognised is that the team is also great for raising awareness with the general public about stomas. It's also helped the profile of our charity no end as well!

This year's season started on Easter Saturday with a game against Medway Dragons. Seven–year old Max Lyons who has a stoma was our mascot for the day and also made a guest appearance on the pitch!

The timing of the match couldn't have been better, coming as it did at the end of a great week for **Colostomy UK**, where the team had hit the headlines in the national and trade press. This was all thanks to ex–Great Britain, England, Bradford, and St Helens prop, Paul Anderson bravely revealing how he had spent part of his career living with a stoma. The initial coverage in the Guardian and Forty–20 magazine, paved the way for more in–depth features on BBC News online, BBC Sport and the BBC 5 Live Rugby League podcast.



June took us to Lancashire and a game against a Chorley Panthers select team. Guest appearances from Warrington and England's Josh Charnley, Jamie Ellis of Castleford Tigers, Owen Farnsworth and Anthony Gelling from Widnes Vikings, helped boost the crowd to over 400. The event also attracted significant publicity, including articles in the Lancashire Evening Press and the Chorley Guardian. Anthony Gelling also produced a fabulous video for us prior to the game. This was an educational piece explaining what a stoma is. It not only helped to generate publicity for the game but served well as a wider awareness piece and was viewed over 100,000 times on social media!

In August we visited Yorkshire as Bramley Buffaloes hosted our game against the Political Animals. The Animals are a representative side featuring politicians from all levels and all political persuasions. This was another great opportunity to engage with new communities and get the stoma message out to a wider audience.

Our last game of the year was in November and saw us play Aldershot & Fleet Masters in horrendous conditions. But this didn't dampen the team's spirits or those of our supporters. The day featured a presentation from 'State of Minds Sport' on the power of sport to promote mental fitness and wellbeing.

We've got lots of exciting plans for 2020 so keep an eye out in future editions of *Tidings* for the latest news!

Charity is the winner as rugby match is played

Day a big success as stars turn out in support

A province of y rough planages reacts to be backed off at the reacty and channing that being with a

Entration sport L. Chorvers Parallelers hanned ED. Ratings (Chorsel) angle and a Gasking Octored hannes for loss Day of bigme of the sector for the office of the sector status. Tari Elizant, a forward frame.

errorise innersity was ton of the and in a debateg lineau between the seal in and about the himself tool a significant search and the search of the and the search of the search of the angle the search of the search of the angle the search of the search o Au-did Charles have have been and the California of the dimensional and the California of the state of the Sector bandle to the sector of the the sector bandle of the sector of the dimension of the sector of the state sector of the sector of the state sector of the sector of the sector sector of the sector of the sector term of the sector of the sector

The plant's and number radius. "Increasing theory processory ing?" and have, while new andres the Treathers' store obtains. "Integrand common wells" of the processory of the

Construction of the second sec



Win up to £25,000 with Unity

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 $\pounds 1$ entry – 50p comes directly to **Colostomy UK**.



How it works

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

How to join — three easy steps

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

 Step three –
 Complete the direct debit instruction or
 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

	- 1		
		A LOT	
www.uni	\mathbf{T}'		' A 4'A ' I (6

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 diei	ts 5 Prize Entries 3 in the next draw digits
	lease print in block capitals) sst Name:		ur Payment method ent by Cheque	I enclose a Cheque made payable to Unity
Jdress:	Postcode: Mobile:	To: The Manager: Address:	Debit Please fill in the	(^(minimum payment £13) form and return to Unity ostal address of your Bank or Building Societ y
O.B.: nail: If you do not wish y	If you would like to receive correspondence via email, plea your name to be publicised if you win, please tick here	ase tick here	:	Postcode:
Payment Freq ow many entries tow often do you	would you like each week?	Account number Banks and Buil accounts. Unity X Service User Num	Iding Societies may not acce Instruction to yo Society to pay b	
vant to pay? please tick payment requency and write imount in box) Fotal Payable	Every 13 wks £13 Every 26 wks £26 Every 52 wks £52	Please pay Unit by the Direct De	your Bank or Building Societ	y this instruction subject to the safeguards assured at this instruction may remain with Unity and, if
Your consent f	D Play (I confirm I am 16 or over and resident of GB)	Date:	that may b may use th	Illy, Colostomy UK may send you samples and information the of interest to you. We do not pass on your details but them to keep you informed of what else is available. If you er not to receive these, please tick the box.
eturn to Unity at th	it into a stamped envelope and Post this fo ne address shown on the right. They stamped en r Unity lottery number.			y: T56

The Unity Lottery, Furness Gate, Peter Green Way, Furness Business ParkBarrow-in-Furness 1 T: 0370 050 9240 1 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

WELLBEING **SUPPORT GARMENTS** Lisa Tate **National Support Manager**

As readers will know, stoma surgery involves bringing the intestine out through the abdominal muscles. By its very nature this type of surgery creates a potential weakness, which can lead to a hernia forming. Parastomal hernias are where the edges of the stoma come away from the muscle, allowing abdominal contents to bulge out through the abdominal wall. An incisional hernia is caused by a surgical wound that has not completely healed and occurs at, or in close proximity to, the surgical incision, through which intestine, organ or other tissue protrudes. Hernias usually develop gradually and increase in size over time. If you suspect you have a hernia, it is very important to consult your stoma care nurse, as a hernia can affect stoma function and, in rare cases, lead to complications that require emergency surgery.

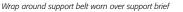
If you have a hernia, your stoma care nurse will carry out an assessment, using this to formulate an individual management and treatment plan. This may include a referral for a professional support garment fitting/ consultation. As well as being invaluable for the management of parastomal and incisional hernias, support garments also help with hernia prevention. They can be worn during exercise or activities such as lifting, gardening and housework, to improve comfort and support the weight of an existing hernia. They also help to conceal the hernia/stoma. This can help with the wearer's body confidence, by bringing an added sense of security when going about daily life. Support garments can also be used as a discretion belt during intimate moments.

Most support garments are available on NHS Prescription, but prior approval is required from your stoma care nurse or GP. If it is decided you would benefit from a support garment, then a hernia 'fitting assessment' will be carried out. This is usually done by either your stoma care nurse or one of the manufacturer's trained support garment fitting specialists. The assessment includes a measuring service, trying on a sample garment and learning how to apply, wear and remove it. Patients are also told how to care for the garment. Only one garment should be ordered initially, to ensure it fits and is comfortable to wear. This also helps to reduce wastage to the NHS. You will also be advised of the average lifespan of your garment and how to reorder if required.

A follow up call is recommended after you have taken delivery of your support garment. This is to check fit and comfort and to identify and resolve early any issues. Some manufacturers include this follow up as part of their customer care service. It is also recommended that an annual review is carried out to take into account any changes since the last garment fitting took place (such as changes in weight!). Some stoma care nurses and fitting specialists recommend cutting a hole in the garment, although medical opinion differs on this matter. Most ostomates can wear a support garment fitted over their stoma. This offers an even distribution of support to the area of weakness (where the stoma is sited). For the small percentage that cannot tolerate the garment over their stoma due to excessive pancaking, leakages or wearing a convex appliance, a hole cut option will allow the stoma pouch to sit on the outside of the garment and still offer support for a hernia.



CUI International Limited







Support band worn over support brief

Male support airdle

There are various support garments available: support bands, adjustable belts, girdles, boxer shorts and support briefs. Support belts are available in variety of standard depths and lengths. Tubular or pull on belts/bands offer a more seamless type of support and again are available in a variety of sizes and depths. Female and male girdles are usually available in low and high waist with a wide range of sizes to meet individual needs. Some manufacturers also offer a bespoke service if a standard garment does not fit a person's needs. Different support levels are widely available and appropriate level of support will be recommended by your stoma care nurse or support garment fitting specialist. Ostomy underwear is also available for men and women, with a range of styles and designs to choose from. This comes with an internal pocket to hold and support a stoma bag. Underwear may be available on prescription but this will depend on local policy and prescription costs. Support underwear is also available to purchase direct from manufacturers. Prices are usually competitive (with the high street) but come with the added features and benefits for an ostomate.

If you have wondered about support garments, or are perhaps about to have an assessment for one, then I hope you have found this short article useful. At CUI, we like to think that we are here to support you!

Colostomy UK: focus on fundraising



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

Why should you fundraise for Colostomy UK?

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

Review of 2019



It's been a record breaking year for fundraising at Colostomy UK with more people taking on more events or challenges, and raising more funds than ever before. Thank you to everyone who has supported us in 2019!

Here are just a few of our highlights!

- Robert Gale (Wye Valley 10K), Richard Hubbard (Stockholm Marathon), pictured inset top, Michael Anderson (Great North Run), pictured inset bottom, and Emma Raynes (Three Marathons in three days) all took on some fantastic track challenges for us.
- Barbara Milleret, and Mark and Samantha Nevey climbed Snowdon.
- * Tasha Critchley swam the equivalent of the English Channel.
- Charlotte Brown and Martin Singleton both chopped off their flowing locks while Nigel Lincoln dyed his beard blue!
- Steve Fisher held a charity football match, and the team at CEVA Logistics walked the 45 kilometres distance from Herne Bay to Sandwich.

- Cheryl and Chiron, pictured on the left, walked up Moel Famau, and Laura MacKenzie powered through 500 kilometres on her exercise bike.
- Just like previous years there have also been literally dozens of you supporting us through holding craft and cake sales, dinner parties, Concerts, Quiz Nights, birthday party donations, and Group walks.

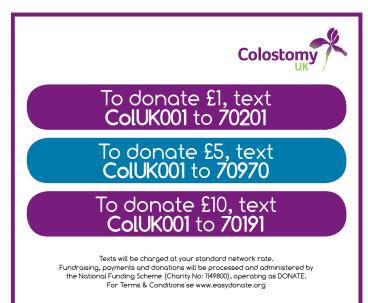
Finally, and while technically in 2018, our 50k Challenge also raised £11,396 all of which was reinvested in our Active Ostomates[®] project, helping us to get more people active in 2019.

SOMETHING

Get involved!

Hopefully some of the people above will inspire you to fundraise for Colostomy UK in 2020. A successful event doesn't need to raise huge amounts of money. We've got plenty of fund-raising ideas to help get you started. If you would like one of our brand new fund-raising packs, which also includes lots of hints and tips about organising an event, then call us on 0118 939 1537 or e-mail fundraising@ColostomyUK.org

Text giving



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

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

Thank you!



We'd also like to acknowledge a few people who have been busy raising funds for us since the last edition of *Tidings*.

- Trish Nicholson, Mariam Idle, Mark Ginger, and Charlie Rowley all asked for donations as part of their birthday celebrations.
- Diane Parsons held a 'Fishy Lunches' tea party afternoon.
- Alex Powis and the team, pictured above, at Pets at Home Walsall who took part in a whole day cycle challenge.
- The Burgin family and all the guests that attended their son's recent wedding.



Support Colostomy UK when you shop with Amazon

Fundrais	sing	Colostomy
	amazonsn	nile
	You shop. Amazon	gives.
search	Step One create an acco smile.amazon.c for Colostomy	unt: :o.uk
and	Step Two remember to g smile.omozon.c 0.5% of every o	o to: :o.uk

Do you shop on Amazon? 0.5% of every order you place will go to **Colostomy UK** if you nominate us as your chosen charity. Just log into your account or create one at **https://smile.amazon.co.uk** and search for **Colostomy Association**. Just remember to always log in through **https://smile.amazon.co.uk** and we'll benefit every time you shop. It's as easy as that!

2019 Raffle

Our annual prize draw took place on 22 November, just in time to catch *Tidings* as it went to print!

1st Prize £2,500	winner was from Surrey.
2nd Prize £1,000	winner was from Devon.
10 x £100	winners were from: Glasgow, Sh Wokingham, Paisley, Glasgow, Devon, Peterborough, Essex and W

Easy Fundraising



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

All you need to do is:

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

For more information or to register just visit

www.easyfundraising.org.uk/causes/colostomyassociation/

CONTINUED ON PAGE 39, COLUMN 1

ropshire,

Stafford,

iltshire.



My Details: Title: Forename: Surname: Home address: Postcode: Telephone (home): Mobile:						
Home address: Postcode:						
	—					
Talanhana (hama):						
Telephone (home): Mobile:						
Email:						
Date of Birth: Month and year of operation:						
Reason for your stoma: Stoma type: Colostomy Ileostomy Urostom	my					
Tick as appropriate: I would like to be kept informed by: Post Email Telephone. Please tick if you would like a receipt I would like to receive information about: Tidings magazine Bag and product manufacturers Colostomy UK, the work it does including training, conferences, volunteer opportunities and fundraising. We will never sell or swap your information with other organisations. You can change how we communicate with you at any time. Call us on: 0118 939 1537 or email: info@ColostomyUK.org						
I would like to make a donation of: giftaid it Thank you for your gift £20 £30 or whatever you are able to give £ I enclose a cheque or postal order made payable to Colostomy UK Thanks to the gift aid scheme – we can reclaim money on yo donation from the government. For every pound you give us, we can reclaim money on yo donation from the government.						
Please debit my Visa/Mastercard/Maestro Card with the amount specified £25 with gift aid, at no extra cost to you.						
Card number (Maestro only) Image: Card number (Maestro only) Image: Card number Image: Card number Image: Card number (Maestro only) Image: Card number Image: Card number Image: Card number (Maestro only) Image: Card number <td>and Tax</td>	and Tax					
Signed Date Signature: Date: / 201	19					
I would like to make a regular donation – Instruction to your Bank/Building Society to pay by Banker's Standing Order: To the Manager: (Bank or Building Society)						
Bank Address: Postcode:	—					
Name(s) of Account holder(s):	—					
Account number: Sort code:	—					
	—					
I would like to make a regular donation* of £20 £30 or other amount (please state) £						
monthly quarterly annually starting on the 1st 55th 25th of month: year:						
thereafter until further notice. (Please cancel any previous standing order in favour of this beneficiary).						
*Please allow one month's notice to ensure donation processes through banking system and state your donation amount in words:						
Please pay: NatWest Bank, Market Place, Reading, Berkshire, RG1 2EP	—					
Account name: C.A. Ltd Account No: 88781909 Sort code: 60-17-21	—					
Name: (IN CAPITALS) Signature: Date: / / 2019 T5	56					

Please fill in this form to make a donation. Check your details are correct, then return the completed form by post to: Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA. Telephone: 0118 939 1537 if you have any queries. Registered Charity No: 1113471

Registered with

FUNDRAISING

REGULATOR

We want your stamps!



You can now donate your used and unwanted stamps to Colostomy UK. Please see the image for details.



What will your legacy be?

Legacy gifts both large and small have an extraordinary impact on the people we support.

You may remember reading earlier in the year about the legacy gift that was left to us by Isabel and Derek Jonas. Their gift has allowed us to better support ostomates in the North East of England. Legacies can gifted to the charity to use as it sees fit, or to support a specific part of our work, such as our 24-hour stoma helpline, *Tidings* magazine, our Care workshops, or our Active Ostomates project.

The leaflet includes all the basic information you will need if you are thinking about leaving us a gift in your Will. You can download the leaflet from our website. Alternatively call us on 0118 939 1537 or e-mail us fundraising@ ColostomyUK.org to request a copy.

Unity Lottery



FUNDRAISING

It's now been over three years since the Unity Lottery replaced our 500 Club and we are glad to say that not only is its popularity growing with more supporters taking part 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 34 or online by visiting: www. unitylottery.co.uk Just remember to link to Colostomy UK!

Grants and Trusts

Thanks to the following Charitable trusts for their support, The Zurich Foundation, The Barber Foundation, The Persula Foundation, The Lewis Family Charitable settlement.



News from support groups across the UK

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

If you are thinking of starting a support group in your local area, or are perhaps about to take over the running of an existing one, then please don't hesitate to get in touch with us for advice, Tel: 0118 939 1537 or e-mail: info@ColostomyUK.org

Wessex Stoma Support Group





2019 has been a busy year! Colostomy UK have helped us to run Chair Yoga and, more recently, some Creative Arts sessions. These have seen us using watercolours to capture a rural scene, take a 'Blue Peter' approach to create animals with deco-patch, and using acrylics to paint a picture of a lighthouse. Our members have thoroughly enjoyed these sessions and we hope to do more in 2020.

We had annual BBQ in the beautiful Chalke Valley overlooking the Wiltshire Downs. We took a mini–cruise from Southampton, down the Solent to the Isle of Wight for the day, pictured top– right. We also enjoyed some interesting speakers at our meetings. We plan to finish 2019 with a flourish: Christmas Dinner at a local Hotel and a visit to Salisbury Playhouse for the Pantomime.

2019 also saw us set up a Carer's group for people looking after someone with a stoma. This has been very popular. The group have met four times for cream tea at a local farm shop, taking over the restaurant for the afternoon and discussing their problems. This is being supported by our stoma nurses.

We would like to set up a Young Ostomates group but this is proving more difficult, but we will keep trying! For more information contact: Michael Slater: **wessex.stoma@yahoo.co.uk** or on **01722 741 233 www.wessex-stoma.co.uk**



Stevenage Ostomistics



We have been around for eight years now and thanks to a good committee led by our chairman, Alfred Levy, we have continued to go from strength-to-strength each year.

We are both a support group and a social group. Our support meetings take place on the last Saturday morning of each month at a community centre in Stevenage. There is currently no attendance fee; we manage to fund things through donations (from members and stoma companies) and from the proceeds of our raffle. We regularly get up to 50 people attending, and there is always room for more!

We have a speaker at meetings. Over the years we have enjoyed talks on a whole range of topics. Most recently we learned about the remembrance poppy and its journey from the fields of Flanders. This was a particularly memorable and poignant talk, well–illustrated by the speaker with photographs and poems. There were moments when the hall was so quiet you could have heard a pin drop. Meetings always close with chair yoga. Next year we plan to do some Creative Minds arts sessions.

Outside of monthly meetings many of us socialise together too. This includes pub lunches and evening pub meets to play dominoes and cribbage in the winter and Pétanque in the summer. This is followed by a meal. We also have an annual barbeque and organise outings, such as our recent trip to the Royal Hospital Chelsea, where we had a guided tour from a Chelsea Pensioner. Our Christmas lunch is a yearly highlight. This takes place at a local hotel and is subsidised from our funds.

If you would like to find out more, or want to come along please contact: Judy Colston 01438 354018 / email: neilcolston@btinternet.com



Another successful Shropshire BOTs open day

The 4th B.O.T.s Open Day took place on 3 October and was attended by more than 120 people this year. With 14 suppliers and distributors to talk to, plus Shrewsbury & Telford Hospital, Lingen Davies Cancer Charity, Disability Oswestry, Bowel Cancer Wrexham, Crohn's & Colitis UK and Macmillan Support, there was plenty for people to see,

There were talks by Jude Williams, from St Martins on gardening with a stoma and Alex Browning of Dansac on skin care.

We were also delighted to receive a visit from Shirley Jones and her husband, Steve Groves and his wife together with Susan Gillham, all members of Aberystwyth Stoma Support Group who travelled up to support us.

Irene Constable

Mid Devon Ostomy Support Group

Janice Ford reports:



Over 20 people managed to come along to our November meeting, despite the torrential rain! We enjoyed a talk by the Devon Freewheelers who are a charity that deliver blood, milk for babies, and medical notes to hospitals by motorbike. We had Christmassy raffle prizes and, as usual, I didn't win anything. Cliff my husband won second to last prize...of six mince pies. I wasn't impressed as I make my own! Oh well better than nothing or the joke that I win the embroidered handkerchief that no one wants!

Meetings: Our dates for 2020 are Saturday 22 February, 4 July and 7 November.

Venue: Boniface Centre Crediton (EX17 2AH) 2:00–4:00pm

Meetings are a social event with light refreshments. Raffle donations are welcome.

For further details e-mail Janice: janice234ford@gmail.com

or, telephone: 07923 975 051 or 01884 799 369

Stoma care open days



Attending a stoma care Open Day is an opportunity to find out about all the ostomy products and services available. It is also a chance to meet other people who have a stoma and visit 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.

We are not aware of any forthcoming open days for the next quarter at the time of going to press, however keep an eye on our website for up-to-date information: www.ColostomyUK.org



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

National support organisations

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

UA Urostomy Association

www.urostomyassociation.org.uk Telephone: 01386 430 140 e-mail: secretary@urostomyassociation. org.uk

Mitrofanoff Support

www.mitrofanoffsupport.org.uk Telephone: 07903 382 013 e-mail: info@mitrofanoffsupport.org.uk

Purple Wings

www.purplewingscharity.com e-mail: lauren@purplewingscharity.com

IOA International Ostomy Association www.ostomyinternational.org

Junior Ostomy Support Helpline (JOSH)

via the Colostomy UK 24–hour free helpline: 0800 328 4257 e–mail: info@ColostomyUK.org

Breakaway Foundation

www.breakawayfoundation.org.uk Telephone: 01283 240 253 e-mail: info@breakawayfoundation.org.uk

Bowel Cancer UK

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

Macmillan Cancer Support

www.macmillan.org.uk Telephone: 0808 808 0000 Monday-Friday, 9am-8pm

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

The IBS Network

www.theibsnetwork.org Telephone: 0114 272 3253 e-mail: info@theibsnetwork.org **Support groups** are places where people can share personal stories, express emotions, and be heard in an atmosphere of acceptance, understanding, and encouragement. Participants share information and resources. By helping others, people in a support group strengthen and empower themselves.

If, you are thinking of starting a support group in your local area, or are perhaps about to take over the running of an existing one, then please don't hesitate to get in touch with us for advice, Tel: 0118 939 1537 or e-mail: info@ColostomyUK.org

Stoma support groups in your county

Channel Islands

Guernsey

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

Jersey

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

England

Berkshire

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

790 558 WAMS (Windsor, Ascot, Maidenhead &

Slough) Stoma Support Group If you are interested in joining then please e-mail Giovanni: info@ColostomyUK.org or call on 0118 939 1537

Bristol

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

Buckinghamshire

High Wycombe Stoma Support Group Telephone 0800 318965

Milton Keynes Stoma Support Group (MKSSG)

Morag Harvey (Secretary) mkssg.sec@gmail.com 07843 768 386 You Are Not Alone Stoma Support Group Carla 07846 354 918

e-mail: carlawright0502@gmail.com

Cambridgeshire

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

Cheshire

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

East Cheshire Stoma Support Group Catherine McIntosh: 01477 535 071

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

Warrington Ostomy Support Group Louise or Joan on 01925 454 813

Cleveland

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

Co. Durham

Bishop Auckland Stoma Care Group Mrs Maureen Davison tel: 01388 818 267 email: trebornosivad@tiscali.co.uk

Darlington Support Group Margaret Clothier, telephone number 0191 333 2184

Durham Stoma Support Group Lynn Ridley,

telephone number 0191 333 2184

Cornwall

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

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

Lanhydrock Ostomist Group

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

Cumbria

Grange Cancer Support Drop in Marie O'Connor 01539 533 279 Stoma Support Groups in North Cumbria Stoma Care Nurses 01228 814 179

Derbyshire

Diverted Local Stoma Support Group Diana Manning: 01283 541 311 F.I.S.H.Y.S. (Friendship, Information, Support & Help for Young Ostomates (age 18-45) Email for more details: fishysderbyshire@gmail.com

Devon

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

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

Plymouth & District Bowel Cancer Support Group

Wendy Wilson - Facebook: Plymouth Bowel Cancer

Dorset

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

Dorset) Colin Clare - 01305 853 238

Essex

Connect

Lin Hart 01279 505 273 email: comeconnectwithus@gmail.com Mid Essex Stoma Support Group Paul Foulger: 01245 224 374

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

Optimistic Ostomates

Angela Taylor 01702 385 510 Redbridge Ostomists Club

Stoma Nurses - Chris/Lisa: 020 8970 8321

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



Hampshire

Replummed stoma support group www.replummed.me

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

For information tel. 07527 707 069 or solentostomates@hotmail.co.uk

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

The Hampshire Ostomates Support Group

Contact Nicki Beare on 07771 558 458 or email: Hampshireostomatesgroup@ gmail.com

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

Wessex Urology Support Group Mrs Jo Stacey: 07910 786 978

Herefordshire

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

Hertfordshire

Ostofriends Stoma Support Group (Potters Bar) ostofriends@gmail.com or

call 07596 748 376 **Stevenage Ostomistics** Judy Colston: 01438 354 018 / neilcolston@btinternet.com

Isle of Man

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

Isle of Wight

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

Kent

Ashford Stoma Support Group Carole Hobbs: 01303 814 014 Atoms Support Group Maria Culleton, SCN: 01227 769 679 or 07827 997 424

Dartford Ostomy Group Support

(DOGS) Tracey or John: 07779 155846 or 07948 974 350 or

dogs-uk@hotmail.com

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

GOGS (Gravesend Ostomy Support Group)

Tracey: 07779 155 846 or Helen: 07710 780 958

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

Tracey: 07779 155 846; Helen: 07710 780 958 or email mogs-uk@hotmail.co.uk

Maidstone Stoma Support Group Judy/Kirsty: 01622 224 305

Sheppey Ostomy Group Support (SOGS) Shelley 07714 734 194 sogs-uk@hotmail.com SWANS Stoma Support Group -Swanley Heather - 07711 445 312 heather601@

virginmedia.com

Thanet Stoma Buddies Support Group Kathy 01843 291 825

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

Lancashire

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

North Manchester and Bury Stoma

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

Oldham Stoma Support June Wilde: 0161 312 5538

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

Leicestershire

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

Lincolnshire

Friends East Coast Support Group Betty Williams - 01205 724 120, Sheila - 01205 364 493 Grantham Support Group

Bobbie/Rachel: 01476 464 822

London

Bowel & other Cancer Support Newham

020 8553 5366

Homerton Hospital Bowel & Stoma Support Group

Angela Davy: 020 8510 5318 or

020 8510 7599

Newham Stoma support group Contact Lauren King 020 7055 5576 **Rectangle - Colorectal Cancer Support** Group

Regina Raymond 020 7472 6299 South Woodford Support Group Nurse Christina and Lisa: 020 8535 6563

Surrey & South London Bowel Cancer Support Group .

Sue Berry: 01737 553 134 or John Amos: 020 8668 0796

Time 2 Talk

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

Merseyside

Bowel Cancer and Stoma Support Group (BeCauSe Group)

For further details please ring 07948 120 955 I.C.U.P.S

Sue: 07742 237 013

St Helens Cancer Support Group Denys Floyd- 01744 884 097

Barbara Harris 01603 417 046 / 07789 581 312 STARS (SToma And Reconstructive

Surgery social support group) Sylvia Hughes 01263 733 448 sylvia.ruth.hughes@gmail.com

Northamptonshire

Facebook too)

Middlesex

Norfolk

Group

Inside Out

Sarah Varma: 0208 235 4110

Bob (chairman): 0208 428 4242

James Paget Ostomy Support Group

Kings Lynn Ostomy Friendship Support

Norfolk Ostomates Support Group (on

Sandra Hutchings: 0150 258 5955

For more info call 01553 775 698 /

01553 674 962 / 01553 768 271

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

Northumberland

Berwick Ostomy Support Group Bobbie Minshull: 07714 479 320

Hexham Ostomy Group

Judith on 07967 927 286 Northumberland Cancer Support members@

northumberlandcancersupportgroup. co.uk

Nottinghamshire

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

Rosemary Brierley: 0115 982 6691 Nottingham Stoma Support Jenny or Kate: 0115 962 7736/

Mrs B Heath: 0115 966 3073 Shropshire

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

Somerset

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

Staffordshire

County Stoma Group Christine Bryden 07757 911 726 or e-mail: countystoma@yahoo.com

Outlook The North Staffs Ostomy

Support Group

Moira Hammond 07788 402 195 or e-mail: cm.hammond@ntlworld.com

Suffolk

East Suffolk Ostomy Group Marion Fisher: 01473 311 204

James Paget Ostomy Support Group Sandra Hutchings: 0150 258 5955

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

Surrev

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

SUPPORT

Normandy Colostomy Support Group Robin Young robin.young11@ btinternet.com 01483 417 610 www.normandystomagroup.wordpress. com

Stoma Support Group Robin Young: 01428 723 255

Sussex

Brighton & District Support after Stomas (SAS)

Sylvia Bottomley: 01273 554 407 Chichester Stoma support Group The Stoma Care Team 01243 831 527

The Ostomy Friends Group

Jane Quigley: 01323 417 400 ext 4552 West Sussex Princess Royal Stoma Support

Tina Walker: 01444 441 881 ext 8318

Tyne and Wear

Gateshead Stoma Patient and Carer Support Group

Stoma Care Nurses: 0191 445 3152 or email stuart.sutcliffe81@yahoo.com NHS Molineux Support Group

John Burchell 0191 265 1047

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

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

Sunderland Support Group Michele Downey 07704 949 30

email: micheledowney@outlook.com

Warwickshire

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

West Midlands

Coventry Stoma Support Martin - 07947 385 643

Wiltshire

Swindon IA www.swindon-ia.org.uk

Wessex Stoma Support Group

Michael Slater: wessex.stoma@yahoo. co.uk or on 01722 741 233 www.wessex-stoma.co.uk

Worcestershire

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

Yorkshire

Acorn Ostomy Support Group 07580 693 155 (After 6-00pm) Airedale Stoma Support Sue Hall: 01535 646 373

Barnsley Bottoms Up Stoma Support Group

Stoma Nurses 01226 4325 28 or Celia Utley (Chairman) 01226 284 262 Behind You (Calderdale & Huddersfield Bowel Cancer Support Group) Stoma Care Nurses: 01484 355 062 Bottoms Up (for urology and colorectal

cancer patients) John Whelpton 07974 657 146 email: midyorks.bottomsup@gmail.com Bradford Stoma Support Group Please get in touch with Lisa Hall on

44 | TIDINGS 56 | WINTER 2019

07552 276747

Dewsbury & District Stoma Support Group

June 07884 003945 or email dews. ssg@gmx.com

Hambleton and Richmondshire Ostomy Support Group

Stoma Care Nurses - Judith Smith and Mary Hugil 01609 764 620 / 07736 295 131

Harrogate Stoma Support group Stoma department office ,ï® Nurse Gill Wilson/Fiona Holtham 01423 555 786

Leeds Bowel Cancer Support Group

Lynda Castle (Colorectal Nurse Specialist) 0113 206 5535 Scarborough Stoma Support Group Stoma Care Team: 01723 342 388 The Hull and East Riding Colostomy

Support Group Pete Smith: 07989 565 335 or Pete

Rennard: 07939 518 642 / 01482 793 966 www.hercosg.org.uk

Northern Ireland

County Antrim

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

Colostomy UK Volunteers Northern Ireland

Chris Wright: 07720 717 771

County Armagh

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

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

County Down

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

Londonderry

Causeway Support Group Mary Kane: 028 7034 6264

Republic Of Ireland

County Mayo

Mayo Stoma Support Marion Martyn: +353 94 902 1733

Dublin

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

Scotland

Ayrshire

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

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

Fife

Fife Ostomy Support Group Ishbel Barr: 01592 772 200

Lanarkshire

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

Moray

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

Scottish Borders

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

West Lothian

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

Wales

Aberystwyth

West Wales Stoma Support Group Shirley Jones: shirleyejones78@gmail.com

Bridgend

Bridgend Ostomy Patients Support Group

Anita Brankley (Sec) 01656 645 602 or bridgend.ostomy@gmail.com

Carmarthenshire

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

Conwy

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

Gwent

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

Cwmbran Ostomy Support Group (COSG)

Philippa Lewis: 01633 791 339 / 07504 713 069

Mid Glamorgan

C.A.S.S Colorectal and Stoma Support Group

Chair person 01685 877 144

Pembrokeshire

PSA (Pembrokeshire Stoma Association) Rosemarie Rees Paton: 01437 532473

Powys

The Bracken Trust Cancer Support Centre

Helen Davies: 01597 823 646

Rhondda Cynon Taf

Royal Glamorgan Stoma Care Support Group

WEBSITE: WWW.COLOSTOMYUK.ORG

Domenica Lear 01443 443 053

Glynis Jenkins: 01792 418 245

Swansea Swansea Ostomy Self Help Group



Colostomy UK literature range

Have you seen our extensive range of support literature? Suitable for ostomates, family members, friends, carers and healthcare professionals.

To order your complimentary copies contact us by:

adminline: 0118 939 1537

eMail: info@ColostomyUK.org

website: ColostomyUK.org/information



Active Ostomates Sport and Fitness after stoma surgery



Projects Flyer



Caring for Colostomates



Caring for a person with a stoma and dementia

-2





-2



Fundraising

YOUR WILL, YOUR

LEGACY

Legacy Flyer

Pack





Helpline Cards



How will a Colostomy affect me?



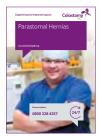




Booklet



Pain & Discomfort



Irrigation DVD

(nurses)

Parastomal Hernias



Irrigation DVD

(patients)

Dootol ge





(colouring book)



Tri-Charity Leaflet



Living with a stoma



One to One (join us) Flyer

Stoma

Reversal





Tidings Magazine



Travel Advice

21	Rectal Discharg
Travel Cer	
Impartant information for traval auto	deserved at
Must is a stored	/ /
A stores is a surginally created spaci- biodatar is desmad to that body use modifies.	ng in tha shakaman tirongit ablish tha kasad anallar Ia can ha sallartari in a kag it alama ka "Nahlar"
Everynamic to search the bearse. then	dama .
Be sensitive and empothetic. Other to conduct the search in a union	
On not separate the holder from their Allow the holder is chaptering. "Here gives,	r madeni supplies as they may read them.
INSPORT NAMES	Y
ACCHES	
DOCTORE NAME AND ADDRESS	BURGERY ET MAP

Travel Certificate



Sam has a stoma





Stoma friendly toilet guideline and stickers



Welcome Pack



Every patient is treated with care, dignity and respect, with attention to their individual needs.

Professional, prompt service - Personal consultation and assessment completed in the comfort of the patient's home or at a clinic location.

With our team of DBS certified Support Specialists we ensure that patients and clinicians receive excellent service and dedicated professional care across the United Kingdom.

Our products are supportive, comfortable and offer complete reassurance.



Wrap around hernia support belts with glove pocket for ease of application



CUI International Limited, 31 St. John Street, Leicester. LEI 3WL. T 0116 262 4333 F 0116 262 5911 E Customersupport@cuiwear.com W www.cuiwear.com