Autumn 2023 | Issue 71 | Price where sold: £6.25

Colostomy UK

AWARD-WINNING

Tidings

Supporting & empowering ostomates

THE 7K STEP CHALLENGE

Step UP FOR STOMAS

Join our 2023 Step Up for Stomas annual fundraising challenge PAGE 25

Real stories
Real people

Colostomy UK

Editorial Team

Editor, Writer & Researcher
Richard Biddle

CEO
Libby Herbert

Senior Stoma Care Nurse Specialist
Ambra Bertinara

Colostomate & Volunteer
Jackie Dudley
Gillian Cowell

Ostomate & Volunteer
Jillian Matthew

Design & Production
H2 Creative • Digital
www.h2.co.uk

Dear readers

I hope you have all managed to grab a holiday this summer. Having a break from the daily routine of life is very important, both mentally and physically. If like me you find the rest helps restore your energy levels, then that's good… as it means you have no excuse for not taking part in our annual 'Step Up for Stomas' challenge this September!

Just like previous years it's all about getting active, while at the same time spreading awareness and raising some funds for Colostomy UK. You can find out more on pages 25 – 28. As you will see, it's about doing something that fits you and your circumstances. There's no expectation that participants will climb mountains or run marathons, so don't let the idea of physical activity put you off. In fact, if you are perhaps recently post-op and only just beginning to get active again, then there is no reason why you shouldn't take on the challenge as a team (by coercing a willing partner!)

There should be something of interest for everyone in this edition of Tidings. Sue Rogers talks about stomas and menopause, and how the symptoms of the latter brought back unwelcome memories of what she went through in the lead up to stoma surgery.

Our other real lives story shines a light on another important topic which to my mind doesn't receive anywhere near enough attention: stoma and pregnancy. Jessica Kingsley, who suffers from Crohn's disease, recounts her experience of two pregnancies: the first before stoma surgery and the second after stoma surgery. We have two articles from professionals working in health, both of whom have contributed to previous editions. Ben Saunders from Keele University gives an interesting update on recent/current stoma-related research. In Dear Dietitian, Pooja Dhir covers B12 deficiency and why ostomates need to be on the look-out for this.

Finally, along with Colostomy news, you will find the latest Stoma Aware campaign updates. The latter includes an informative piece from Gillian Cowell (who is on the Tidings editorial board) about how to contact your local MP. This is something that many people have thought about doing in relation to the provision of stoma-friendly toilet facilities in their local area but haven't known the best way to do this. Gillian's article explains what's involved; it is more straight-forward than you might think.

Best wishes,

Richard Biddle
Editor, Writer & Researcher

Colostomy UK

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

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

How to contact us

Stoma helpline for:

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

Adminline for:

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

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

Editorial Enquiries

Letters, articles or other submissions
Colostomy UK, 100 Berkshire Place,
Winnersh, Wokingham, Berkshire,
RG41 5RD
Editor@ColostomyUK.org

Advertising enquiries

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

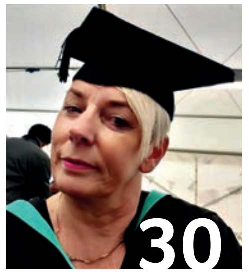
Social media:

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!

WWW.**COLOSTOMYUK**.ORG

Contents



Colostomy UK

Step Up for Stomas 2023

Real Lives

Wellbeing

Support

Donating to Colostomy UK

An annual donation of £25 (or what you can afford) allows us to produce Tidings and to continue our vital work, supporting, and empowering ostomates – see page 41 for our donation form.

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

Colostomy UK

fundraising

Lindsay Waldrond / Fundraising Manager
Alice Fitzgerald / Fundraising & Communications Executive
GetInvolved@ColostomyUK.org

Fundraising is vital for charities who do not receive any type of government grant. This is why we are so grateful to our wonderful supporters and all their fundraising efforts. Without you we would struggle to provide the many services that people with stomas have come to rely upon, such as our 24-hour Stoma Helpline, the information and advice literature we produce and, of course, Tidings magazine.

What many people don't appreciate is that for Colostomy UK, fundraising is important for reasons other than just money. It also makes a vital contribution to our Stoma Aware campaign by raising awareness and educating people within the wider community about what stomas are, the challenges people with them face and the work that Colostomy UK does. As anyone who has donned one of our t-shirts and taken on a challenge like Step Up for Stomas will know, people ask questions and want to know what and who it is you are raising funds for!

Here are a few examples of the many individuals and teams of people who have been and are fundraising on behalf of Colostomy UK:

After the biggest challenge of her life, Sue is about to face another one!

One day in January 2023 at the age of 58, Sue who lives in Yorkshire, was rushed into hospital for life saving, emergency surgery and woke up from her operation with a permanent ileostomy. Although Sue had worked as a nurse so knew about stomas, nothing could have prepared her for this sudden change in her life:

"'Alfie' became part of my life in January this year. For some unknown reason the blood supply to my bowel stopped and caused my colon to die. I became very poorly very quickly, developing toxic mega colon and septic shock. I was told by the consultant that I would die without immediate surgery and might not even survive the surgery, but I did! I now have a permanent ileostomy - Alfie. I am adjusting to a completely different life. It is definitely a love hate relationship I have with Alfie but without him I wouldn't be here today, he saved my life. It hasn't been easy adapting to life with a stoma, there are so many things you have to think about, so many things to be anxious about but I am starting to appreciate the good things when they happen."

Sue is undertaking the Skipton to Bingley Five Rise Locks, a 13-mile walk, on 9 September 2023 with the support of her close friend Debbie and family, to fundraise for Colostomy UK and raise awareness of the needs of ostomates.

"I didn't ask anyone to join me on the walk, but Debbie immediately said she would walk the whole distance with me, and my family have all said they will do parts with me and all be there at the finish. It shows how supportive they are, and how they realise the importance of raising money to make people more aware of how stomas affect lives."

Please support Sue in her fantastic fundraising effort by donating to her 'Just Giving' Fundraising Page:
www.justgiving.com/page/sue-lane-1686598970525

A big THANK YOU to Katie!

Katie Brien was 27 years old in the summer of 2022 when she was admitted to hospital for surgery, which resulted in her having a stoma. Thanks to support from her partner, family and friends she kept going through this difficult transition in her life:

"I have the most incredible partner, family, friends, and people around me who kept me positive and going throughout the whole ordeal! I am now better than I have been for three years and learning to live with my 'new normal'. So I figured why not challenge myself to do something to keep me active and moving!"

After undertaking the Lincoln 10k run in April of this year, Katie Brien raised an amazing £4,699 for Colostomy UK.

Netball nets thousands in donations

When Chelsey Fitzgibbon underwent a preplanned ileostomy operation, she credits the surgery with saving her life:

"…the stoma saved my life - literally! I now have my life back and can do anything I want and eat anything I like".

However, Chelsey had to learn to adapt to her new normal, especially when playing netball, a passion of hers since she was seven years old:

"I have had to make a few adaptations when I play Netball and that's wearing a support belt and a cup to protect my stoma, but other than that I have been able to get back playing."

Since surgery, Chelsey says her confidence has continued to grow and so she organised a Mixed Netball tournament which took place at the start of July in Swindon to raise funds for Crohn's & Colitis UK, and Colostomy UK.

Chelsey raised an amazing £3850.65 from the day.

Legacy

Leaving a gift in your will to Colostomy UK will make a real difference to the support we are able to give to the ostomates of today and tomorrow. If you'd like further details of leaving a gift to us, please visit our website and search 'legacy' or call our Adminline 0118 939 1537 and we will send you a copy of the booklet pictured.

E-ngage with us!

Go online to access all the support you need from Colostomy UK

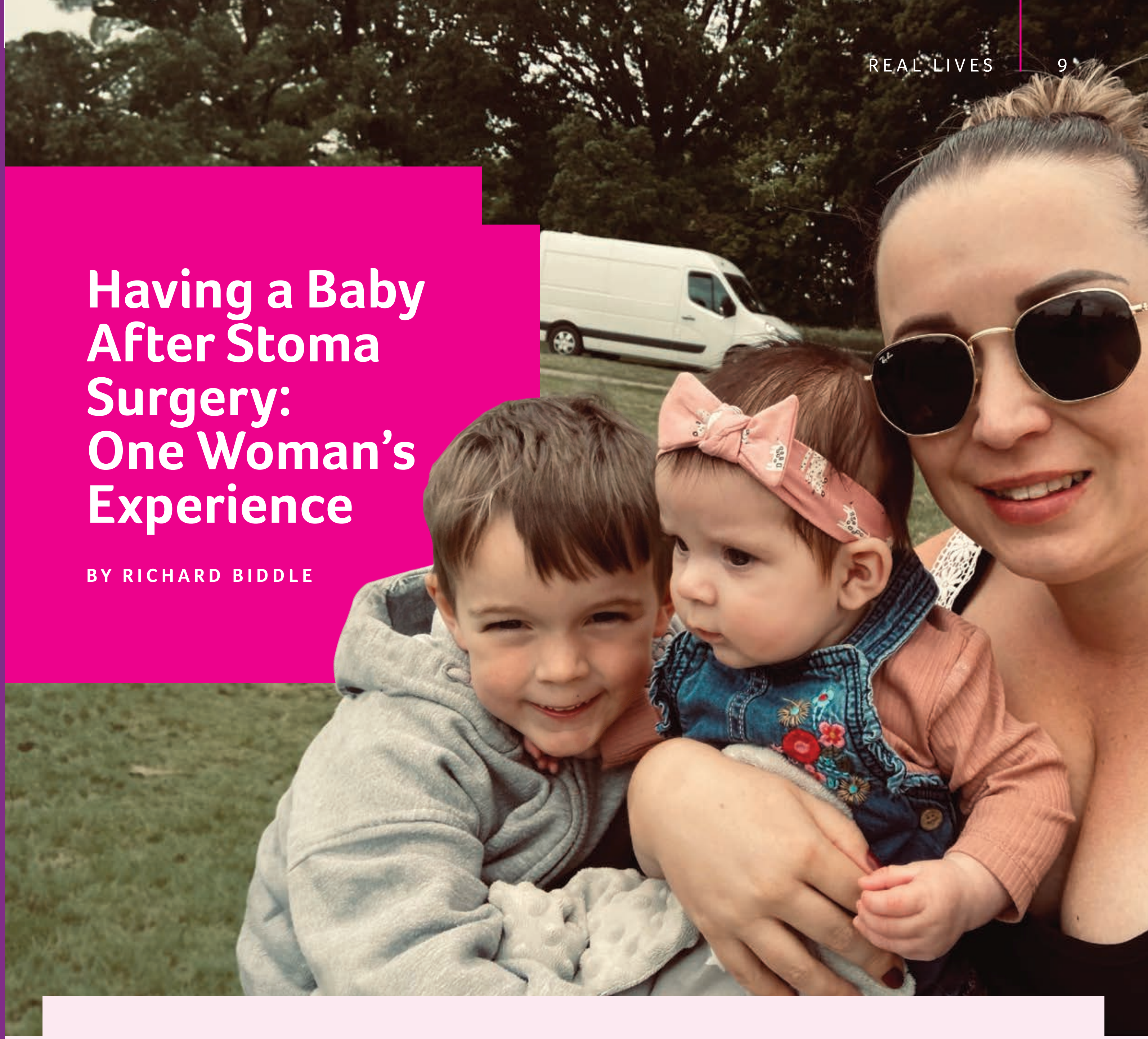
Visit our website: www.colostomy.org.uk for downloadable versions of all our advice booklets, information on stoma support groups and events, the latest Active Ostomates classes and practical guidance on living with a stoma.

And while you're there, subscribe to our free, monthly e-newsletter delivered straight to your inbox.

Or connect with fellow ostomates, their family and friends in our private Facebook Group. Search Colostomy UK Support Group Facebook and click to join.

Why not share your news on Instagram and Twitter: @ColostomyUK

...and get involved!



Having a Baby After Stoma Surgery: One Woman's Experience

BY RICHARD BIDDLE

> **It was around this time last year that one of our volunteers, a young woman, said to me that more needed to be done for women with stomas who were pregnant or wanted children.**

Afterwards, when I checked what was available in terms of support, advice and encouragement, I rapidly came to the conclusion she was right. The existing patient literature is far from comprehensive. Similarly, when I searched 'pregnancy and stoma' on Facebook it yielded plenty of support groups, but none in the first 60 (I gave up looking after that) made any reference to stomas whatsoever. Of course, this doesn't mean that such groups don't exist. But if nothing else it illustrates how difficult it is for women with stomas to get ostomate-to-ostomate peer support while they are trying to conceive, during their pregnancy or afterwards as new mothers.

This article makes a start at addressing the paucity of information out there. It is about a woman called Jessica and her two pregnancies: the first before stoma surgery, the second after. What follows focuses primarily on Jessica's experience of being pregnant as an ostomate, rather than on the illness that led to her needing stoma surgery.

Jessica lives in Buckinghamshire with her partner Karl, children Lucas and Evelyn, and the family's two dogs. Jessica was diagnosed with Crohn's disease when she was 19. This followed four years of feeling unwell, undergoing lots of tests, and watching puzzled doctors scratch their heads.

It took some time to get Jessica's Crohn's under control. She went through all the known medications and had intestine resection surgery all to no avail, before going on a trial for a new experimental drug, which worked. Jessica became pregnant with Lucas towards the end of 2017 when she was 26 years old.

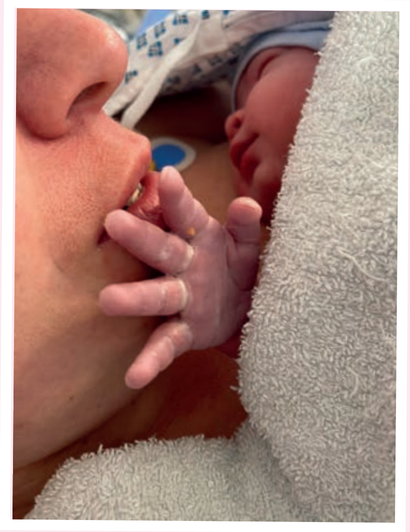
When a woman with Inflammatory Bowel Disease (IBD: Ulcerative Colitis and Crohn's disease) becomes pregnant many medical considerations come into play. In simple terms, the pregnancy can affect IBD and IBD can affect the pregnancy. For women with the disease in remission at the time of conception the risk of a flare-up remains similar to non-pregnant women. Conversely where the disease is active at the time of conception, persistent flare-ups can accompany the pregnancy. Each woman is to an extent a unique case, requiring complex decisions to be made about important issues such as whether to continue with existing IBD medications, find alternatives or perhaps even stop medication altogether.

Jessica had a difficult first pregnancy. As the impact of the experimental drugs on her unborn baby were not fully understood, she was initially taken off of them. Very soon afterwards she had the first of many terrible flare-ups. Six weeks later she was put back on the drugs, as this was considered the lesser of risks and preferable to her losing the baby. Even back on the medication it proved impossible to control Jessica's Crohn's. 19 weeks into her pregnancy she was put on bed rest, where she stayed for the remaining four months. It was a period characterised by sickness, pain and flare-ups and frequent visits to hospital. This was because each time something happened, it needed to be established whether what she was experiencing related to her baby or to her Crohn's. In the end she was admitted to the Women's Centre at the John Radcliffe Hospital, which is a regional referral unit for high-risk pregnancies.

All in all, it was a stressful nine months, which ended happily in August 2018 with delivery by C-section of a healthy baby boy. After Lucas was born (and before her stoma surgery) Jessica was advised not to have any more children, given how her Crohn's had interacted with her carrying. Around a year after Lucas arrived, Jessica had stoma surgery. The need for this was not connected with her pregnancy. Jessica had known for some time that she would probably need a stoma. Her healthcare team were just unable to be specific about when this would be necessary.

> **Once she had recovered from the surgery and started to adapt to life with a stoma, Jessica and her partner began to think about having another child.**

They were buoyed by hearing from Jessica's Crohn's doctors that now she had a stoma, it should be possible to keep her condition in check, should she fall pregnant again. Even so, the decision wasn't one that the couple took lightly. Jessica believes that, ultimately, the difficult experience of her first pregnancy gave her and Karl the confidence they needed to try for another baby. As a consequence of being able to mentally prepare, Jessica developed a positive mindset, thinking along the lines of: "It's only nine months, I coped last time, I can cope again. If it's better than last time round, then that's a bonus." By the middle of 2022 Jessica was expecting again.



Jessica enjoyed a much easier second pregnancy. There was no forced bed rest or unplanned hospital visits. She stayed on her Crohn's medication throughout and had no flare-ups. Evelyn was born safe and well in February this year. From the point of view of being pregnant when you have a stoma though, it was not an entirely uneventful nine months.

Although Jessica received little in the way of specific antenatal stoma advice, she was informed that stoma function could be affected. Jessica was told to keep an eye out for possible blockages which could occur if the baby was lying in a particular way. She was advised that if she had no function for a day and a half then she was to call her doctor or go to A&E, so that the issue could be resolved (perhaps by moving the baby). In the event, Jessica did not have any blockages, but the consistency of her output did alter. Almost as soon as she became pregnant, she started to experience constipation.

The next thing of note to happen was that the size and shape of Jessica's stoma changed. It developed a mushroom shaped head. This was not something Jessica was prepared for, and initially found a bit scary. Calls to her doctor and stoma care nurse did little to alleviate her unease. She sensed that neither really knew the cause. They speculated that it was connected with the baby getting bigger, but couldn't be sure, which Jessica found frustrating. As her stoma wasn't hurting, a plan of 'wait and see' was adopted. It was only after Jessica posted what was happening on the Colostomy UK Private Facebook Group, that she started to feel happier: someone responded to say that the exact same thing had happened to their stoma when they were pregnant.

Finally, during the last month of her pregnancy, the edge of Jessica's stoma began to bleed, and she started to feel what she describes as 'pressure' pain. She again sought medical advice and was told that both the bleeding and the pain were likely due to the fact that the baby was getting bigger. Again, this wasn't the definitive answer that Jessica had hoped for. It left her feeling like being pregnant and having a stoma was something that was a little out of the ordinary. She was told to take normal painkillers and that the issue should resolve itself after her baby was born (which it did). On a humorous note (but also something that would-be ostomate mums need to be aware of) Jessica says to look out for the baby kicking.

During the third trimester she swears that Evelyn was using her stoma as a target!

Jessica testifies to having felt very daunted by the prospect of being pregnant as an ostomate. But as her story shows, it is possible to have children after stoma surgery. Of course, not every pregnancy is planned, but where feasible it is sensible to discuss matters with your doctor and stoma care team as soon as you can. Their advice (on everything from potential issues with conception, to the pregnancy, and then birth) will take into consideration your particular circumstances, including the reason(s) why you had stoma surgery in the first place. Jessica's experience also highlights some of the difficulties expectant mums with stomas can face getting definitive answers when odd things happen and the problems of connecting with other women in similar situations. As you will have noted, this was where members of our Private Facebook Group came to the rescue. Although they couldn't give the answers Jessica craved, they were able to reassure her from their own experiences. On a final note, since speaking to Jessica, we have begun the research and work needed to put together a Colostomy UK advice/information booklet. The volunteer I mentioned at the start of this article is helping with this and has already managed to recruit a senior stoma care nurse to the team!


Kirsten

WHEN A STOMA BAG FITS RIGHT
IT FITS EVERY SIDE OF LIFE

Coloplast

Take the Ostomy Check and check your stoma health

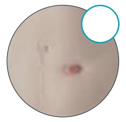
We understand over time that the size of your stoma, your body shape and lifestyle can all change. That's why it's so important you regularly check your stoma care routine and stoma health. As well as ensuring that you are still on the best product solution to fit your body shape, you will feel secure and confident in your everyday life.

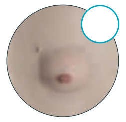
Why not take the Ostomy Check today to help you identify common issues such as sore skin, or problems with adhesion and leakage. We'll then review your answers and a member of our dedicated Coloplast Clinical Services team will contact you.

Please tick in circles where appropriate

Which best describes the area around your stoma?


○ Regular
The stoma opening is above or level with the skin surface


○ Inwards
The stoma opening is below skin surface or requires some support due to challenges on dipped areas


○ Outwards
The stoma opening is on curved body shape or outward area (e.g. a diagnosed hernia)

Do you have any adhesion issues?

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

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

Do you have any skin irritation issues?

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

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

Do you have any pouch issues?

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

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

For two-piece product users only

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

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

By completing this coupon, one of our Clinical Services team will contact you to discuss your answers. Simply post back by sending to **FREEPOST COLOPLAST** (no further postal address details or stamp required) and we'll be in touch.

First name: ______________________
Surname: ______________________
Email: ______________________
Telephone No.: ______________________
Signature:
Date of Stoma Surgery: ______________________

By providing your personal and sensitive data, you are consenting to Coloplast Limited that we may process and store your data for the purposes to fulfil your sample request, to keep you informed about it and follow-up via phone, text, email, or post, and to improve our products and services. We may refer you to healthcare professionals if needed. We may share your data with our sub-vendors when necessary to fulfil the request and transfer data securely outside the EU to support our business operations. You may withdraw consent at any time without ramifications, by writing to privacyrequests@coloplast.com or calling us at 0800 132 787. For more information, please visit our privacy policy for consent at www.coloplast.co.uk/about-us/Landing-pages/privacy-notice/

Inspected and rated
Outstanding ☆
Care Quality Commission

Our Clinical Services team is rated **Outstanding** by the Care Quality Commission (CQC), who independently regulate the care our teams provide.

Coloplast

OC_OSTOMYCHECK_DTC_ADVERT_CUK

campaigns

Giovanni Cinque
Marketing & Campaigns Manager
GetInvolved@ColostomyUK.org

Stoma Friendly Toilets UPDATE

You may have noticed an increased amount of content recently about our campaigns, with a specific focus on toilets. We've been campaigning on this topic for many years, but the results our Stoma Aware survey (2022) coupled with recent research which shows a continued decline in the number of public toilets across the UK, has brought fresh vigour to our efforts.

Toilets cropped up time and again in people's survey comments. One theme to emerge was access, with 62 per cent of respondents saying that a lack of suitable toilet facilities had a negative impact on their day-to-day life. Things that most people take for granted, like a trip to the shops or meeting friends for a coffee, were highlighted as being a problem. If these results are representative of the ostomate population as a whole, then this equates to a frightening 125,000 people affected.

Other research suggests the issue is only going to get worse. A Freedom of Information request revealed a 20% drop in the number of local council provided toilets during the period 2016 to 2021. More recently, Raymond Martin, Managing Director of the British Toilet Association was quoted in The Guardian as saying:

> 'We reckon we have lost 50% of all [standalone public] toilets across the country in the last ten years. It's a crisis situation'.

Of course, for people with stomas, access is not the only concern. Access to stoma-friendly toilets is another, as is the fear of being challenged (verbally and physically) when using accessible facilities more generally. Both matters featured in the findings of our survey. In other words, there are plenty of compelling reasons for a call to action!

Getting Involved

While we may not be able to increase the number of toilets, we can certainly make more existing ones 'stoma friendly'. Since we launched our Stoma Aware pack earlier this year, over 100 people have been campaigning to make facilities in their local community suitable for ostomates. We have already had lots of successes from local councils to cafes and cinemas, making the changes required. **If you would like to get involved, then drop an email to getinvolved@ColostomyUK.org and we will send you everything you need to get started.**

Another way you can get involved is to contact your elected representative (Gillian Cowell's article pp. 16-19 tells you how). You may be surprised to know that there is no statutory requirement placed on local councils by central government to provide public toilets. What we would like people to do, is to use the information in Gillian's article to write to or (preferably) email their local MP and explain the impact that the lack of public toilet facilities is having on the lives of people with stomas in their area. You could explain that the lack of a statutory requirement for local councils to provide them is exacerbating the situation and request that they raise the issue with the Department for Levelling Up, Housing and Communities.

In time, hopefully our collective voices will be noticed by policy and decision makers who, through a better understanding of how important reliable access to suitable toilet facilities is for the quality of life for people with bowel and other conditions, will act accordingly.

PS: Don't forget to include us in your communication.

Get your Stoma Aware pack and help us make a difference

Can you help us to make your community become more #StomaAware?

Our Stoma aware pack includes some great resources to help you engage with local businesses and organisations including:

- Stoma Friendly Toilets letter
- Stoma Aware Info poster
- Stoma Friendly Toilets guidelines

To get your pack, email **GetInvolved@ColostomyUK.org** and help us make a difference!

#StomaAware

To whom it may concern

I am writing to request that the accessible toilets in your organisation are made 'stoma-friendly'. This is quick and inexpensive to do and will make a positive difference to lives of many people like myself, who have undergone life-changing surgery.

In case you didn't know, a stoma is a surgical opening in a person's abdomen through which bodily waste is collected in a bag. Stoma surgery is used in the treatment of many things, including bowel cancer, Crohn's disease, diverticulitis, and child-birth trauma. People of all ages have stoma surgery, even babies and children. There are approximately c200,000 people with stomas in the UK, that's 1 in 335 of us.

After you have had stoma surgery, your needs change. In particular it is very important that you have easy access to appropriately equipped toilet facilities. Without these, many people with stomas are fearful about the everyday things in life that most people take for granted, like going shopping, or visiting the cinema, or going to work. In some cases, it can lead to them becoming lonely and isolated.

All a toilet needs to be 'stoma-friendly' is a hook to hang personal possessions, a clean shelf on which to lay out stoma/medical supplies, inclusive signage and a mirror to help with changing a stoma bag. To find out more details I suggest visiting Colostomy UK's website: https://www.colostomyuk.org/campaigns/toilets/ .

You will see that Colostomy UK produce toilet stickers to show that a toilet is stoma friendly. You can obtain these by emailing getinvolved@colostomyuk.org, As well as despatching the stickers to you, the team would be delighted to work on a joint communications piece to promote that your toilets are Stoma Friendly.

This charity also provide other services that might be of interest, such as providing 'Stoma Aware' training to employers and employees (including those in customer-facing roles) and HR departments. So that your employees and customers feel supported and understood.

Yours sincerely

campaigns

Giovanni Cinque
Marketing & Campaigns Manager
GetInvolved@ColostomyUK.org

An Addition to the Stoma Aware Toolkit for All You Local Campaigners!

If you have been following our Stoma Aware campaign updates, then you will know that in recent months we have enjoyed some notable local successes.

Armed with one of our Stoma Aware packs, hard-working and determined ostomates up and down the country have responded to our CALL FOR ACTION and have been doing their best to encourage businesses and organisations (including local government) to make their toilet facilities stoma friendly. We are grateful to everyone who has got involved so far. We like to think of you as our Stoma Aware Stars, going out there to spread awareness and fight ignorance. Local action of this nature supports our work as a charity, as we try to do the same on a national basis. We are under no illusions though, we're in it for the long haul.

Another way in which change can be brought about locally is by engaging with your elected representative. Often though, people are reluctant to do this because they aren't sure how to go about it. Hence, in the latest addition to our Stoma Aware Toolkit, Gillian Cowell who is on the Tidings Editorial Team, explains what's involved. As you will see, it's not really such a daunting prospect after all!

Engaging With Your Elected Representative

My name is Gillian Cowell and I am a Researcher for an opposition MP in the UK Parliament, and am based in Scotland. I have had a colostomy since 2005 due to Crohn's disease.

My job involves providing briefings, reports and information to the MP on issues relating to their role as a spokesperson, as well as on a diverse array of topics that require in-depth research. This research is used in debates, within debates on bills and statutory instruments, in committees, within written and oral parliamentary questions, petitions, meetings with campaign groups, etc. I have a Masters in Research (MRes) and a PhD. I thought it might be useful to write a short article on how to engage with your MP because it can be a good way to raise awareness of important issues.

I will be dealing with how to contact an MP in the UK Parliament but hopefully the information might also translate into useful advice for getting in touch with any elected representative in Scotland, Wales and Northern Ireland too. Also please note that all MP offices are run differently; it is therefore best to get in touch with your local representative to ask how they may be able to assist you with the issues you want to raise.

The UK Parliament and the UK Government

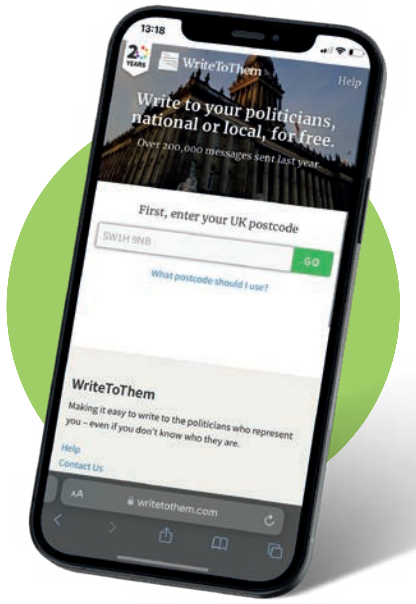
The UK Parliament is responsible for holding the UK Government to account, so it's important to remember that the Parliament is not the Government, but is a separate institution. MPs are responsible for scrutinising and challenging the work of the Government, as well as debating a wide array of issues in the main Chamber, in Westminster Hall or as part of a Select Committee, general committee or joint committee, or an all-party parliamentary group (APPG). MPs also participate in making and changing laws and checking and approving the spending of Government. Some MPs are also government ministers and some have a spokesperson role in opposition.

For how it all works see **www.parliament.uk/about/how/role**.

So, who are my elected representatives?

Any citizen in the UK should first get in touch with their own constituency representative. Everyone in the UK has an MP who represents them in parliament. If you live in Scotland, you will have both an MP and an MSP (Member of the Scottish Parliament). For people living in Wales, you will also have a Senedd member, and for Northern Ireland an Assembly member (MLA).

To find out who represents your area go to **www.writetothem.com**, which will tell you who your elected representatives are, with links to each individual and a form you can fill in to send them a message. The resource also gives a little bit of further information on which matters are devolved to the parliaments and governments in Scotland and Wales.



Write to your politicians, national or local, for free.

Over 200,000 messages sent last year.

First, enter your UK postcode

WriteToThem

Making it easy to write to the politicians who represent you – even if you don't know who they are.

Your elected representative can seek assistance on your behalf on many issues - see **www.writetothem.com/about-yourrep** for an excellent guide on when you should contact your MP, MSP, NI Assembly Member and Senedd Member, and what subject matters they can assist you with. It probably seems complicated but if you write to the 'wrong' person they will let you know and can advise you further on who to get in touch with. Please always remember to put in your address and contact details so they know you live in their constituency. See also **www.parliament.uk/about/mps-and-lords/members**.

Continued overleaf...

I didn't vote for my elected representative or align with their political party or views. Can they still help me?

MPs are responsible to their constituents, the parliament and their political party.

Their main work is to try to help resolve an issue for you as their constituent and to represent their constituents and local issues in parliament. They can do this by raising issues within debates, parliamentary questions and in Early Day Motions (EDMs). If they are unable to help, they may refer you to another organisation. MPs are responsible for representing you regardless of their party and even if you didn't vote for them or align with their views or support their party. However, be aware there is no legal requirement for an MP to agree with you on an issue, as sometimes there can be a conflict between your stance and the interests of the wider constituency they represent or with the policy of their party. They will of course always respect your position and will be happy to discuss it with you.

What can I contact my elected representative about?

Below are just a few examples, but again all MP offices run differently:

1. Your personal circumstances

Your MP can make enquiries on your behalf on a wide range of issues that are affecting you personally, for example, by writing to an organisation, the local council or service to ask them to look into the issue. This is done privately and is called 'casework' and can include personal issues you're having seeking asylum, with immigration issues, housing, benefits, NHS appointments, neighbourhood issues, and many, many more. Note that MPs can't give legal advice. They also represent issues affecting your local community and will always want to hear about these. You can get in touch with your MP by email, phone or through surgeries. Call or email their office for surgery dates and times. Sometimes your MP might want to make the issue public by raising it in parliament – anonymously - through a subject-specific Oral Question time, in Prime Minister's Questions (PMQs) or in a debate. This helps make the issue more widely known about, including bringing it to the attention of the Government minister(s) attending and other MPs.

2. Local Groups

If you run a local group, charity or community-focused organisation in their area it can be a good idea to get in touch with your MP, for example if you need assistance, advice, to ask if they might attend a meeting or event – or even just to let them know of your existence and what you do. MPs are always keen to hear about local groups and really enjoy learning about the work they do in their constituency. And you never know – you might get a mention in Parliament!

3. If you work for or represent a larger advocacy group, charity, third sector organisation etc

Most of these organisations will have a public affairs, press or parliamentary officer who will provide briefings and expert advice to MPs. In the main they will contact MPs they know have specialties or interests in particular subjects and who are active in Select Committees, represent particular geographic areas, and who have spoken about the issue in Parliament. These briefings are extremely helpful and often provide detailed information on how the issue affects people, gaps or issues with a current Bill, law, policy or stance the government is taking, and what changes are needed. If you do a web search for the issue and find an organisation representing that subject, check for any parliamentary briefings, press releases or statements. These are invaluable and an incredible amount of work goes into these – refer to them in your communication to your MP.

I want to draw attention to an issue that I think needs to be more widely known. How can my MP help?

We've already discussed an MP can assist with personal issues you're experiencing. However, if you want to draw their attention to wider issues or gaps in provision, a campaign, or subject or issue you're passionate about, etc. your MP can be a good person to contact. Before you contact your MP think about the following questions first:

- » What do I want from my MP? Perhaps you want to inform them about an issue, seek their assistance in changing something, or attend a meeting you are organising. Think about why this issue matters to you and why you want your MP to assist you.
- » Who else might benefit? Does the issue you are raising affect other people and groups? Do you have any statistics or facts about how many people the issue affects and what the outcome would be if the issue was resolved?

The UK Parliament has produced a helpful guide about what an MP can do to raise matters in the House of Commons. This includes asking questions during Question Time, adjournment debates, backbench debates, and Private Members' Bills. It also provides links to examples - **www.parliament.uk/about/mps-and-lords/members/raising**. Also, the Get Involved page on the UK Parliament site has great advice on contacting an MP, signing or starting a petition, having your say on laws and debates, getting involved with Select Committee inquiries, and much more. **www.parliament.uk/get-involved**.

See also **www.parliament.uk/about/mps-and-lords/members/what** on what your MP can do for you. Many MPs also have a web site which sets out how they can help you and what campaigns they've been involved with to date. Some also write articles in publications such as The House - **www.politicshome.com/thehouse/magazine.htm**, or in their local newspaper, national newspaper or party web site. A really good resource that you can search to see what has been said on an issue is **www.theyworkforyou.com**. At the bottom of the page they have a search bar where you can find debates, written questions and Hansard entries, all in the one place. And of course the Hansard search itself is great - **hansard.parliament.uk**. To view upcoming or previous debates, departmental question sessions, committee sessions and other activities see the What's On page - **whatson.parliament.uk**. The Business Papers also let you know what is coming up in case you want to draw your MP's attention to a debate on an issue that is important to you, to search EDMs or submitted written questions. **commonsbusiness.parliament.uk**.

Be realistic about how much assistance an MP can give

MPs receive a huge number of emails and requests on a daily basis. Whilst your MP will do everything they can to help you, they can't support every cause nor solve every issue. Also, it is up to every individual MP to decide what they can assist you with and whether the campaign you are drawing to their attention is something they feel they can support, taking into account the needs and responsibilities they have to their wider constituency and to their party's policies on the matter.

Helpful Guides

Many charities, trusts, campaign groups, third sector organisations and representative bodies produce guides on engaging with your MP – a simple web search will give you some wider ideas.

A very comprehensive guide is by the Local Trust, **localtrust.org.uk/wp-content/uploads/2021/03/Working-with-your-MP_a-guide-for-communities_FINAL.pdf**. In particular, I like their advice on p.9-10 which includes the following points:

- » How will you get your MP on board?
- » What is your MP interested in?
- » What key message are you trying to share?
- » Be confident and concise
- » Make it personal
- » Encourage others
- » Lead with what you know
- » Be honest
- » Be clear about your 'ask'

And remember: if you are not comfortable with talking about personal circumstances or if anything is too painful you do not in any way need to divulge it. You can raise more general points or write a short research report setting out the issues and why they are important.

I hope this has been a useful article but just a reminder: the above is only guidance - always check with your MP how they work and how they might assist you as every office is different.

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, please download them from our website or contact us by:

Admin line: 0118 939 1537 | **Email:** hello@ColostomyUK.org | **Website:** ColostomyUK.org/information


Active Ostomates sport and fitness after stoma surgery


Campaigns and Projects Flyer


Caring for a person with a stoma

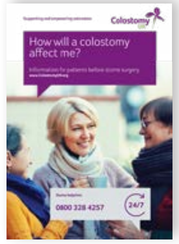

Caring for a person with a stoma and dementia

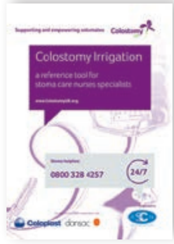

Colonoscopy through a stoma


Fundraising Pack


Healthy Eating

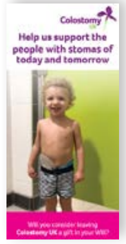

Helpline Cards


How will a stoma affect me?


Irrigation Booklet


Irrigation DVD (nurses)


Irrigation DVD (patients)


Legacy Flyer


Living with a stoma

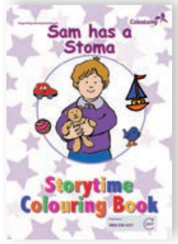

One to one


Ovarian Cancer and stomas


Pain and discomfort

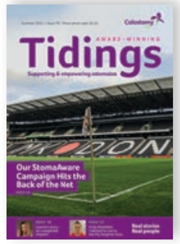

Parastomal hernias


Rectal discharge


'Sam has a stoma' colouring book

Stoma friendly toilet guideline and stickers


Stoma reversal


Tidings magazine


Travel advice


Travel certificate


Tri-Charity leaflet


Welcome pack

TEAM Colostomy UK

campaigns

Giovanni Cinque
Marketing & Campaigns Manager
GetInvolved@ColostomyUK.org

Jo Cox Memorial Rugby League Match

You may remember from the last Tidings that our Rugby League team were building up to a game against the British Asian Rugby Association (BARA). As well as being part of our efforts to inform people about stomas, we hoped the fixture would raise Colostomy UK's visibility within South Asian communities.

The game took place on 4 June at The Fox's Biscuits Stadium in Batley in front of 3,000 spectators, as part of the Jo Cox Memorial Rugby Match. Jo Cox was the MP for Batley and Spen before being murdered in 2016. The event started some years ago in celebration of her life and ran annually until the pandemic. Its triumphant return was organised by Batley Sporting Foundation, in conjunction with More in Common Batley and Spen, and Jo's family, as part of The Great Get Together, which sees a series of events held nationwide. Our game was followed by Batley Bulldogs taking on York Knights in the Rugby League Championship.

Jo's sister Kim Leadbeater, the current MP for Batley and Spen, said:

"It was lovely to see the return of this very special game, and there was an amazing atmosphere throughout the day both on and off the pitch under beautiful sunny skies.

I firmly believe that sport is a brilliant way to bring people together, and the reaction on the day proved that to be the case…

> *The day was everything we wanted… a lovely sporting event, a fun time for all those who attended, and a wonderful tribute to Jo."*

As well as action on the pitch there were activities across the Mount Pleasant site including music from the Yorkshire Groovers Samba Band, and Batley group Gods of Fortune, with local scouts providing food, an inflatable assault course, archery, and games.

In addition to our pitch appearance, Colostomy UK had a stand profiling our work and selling the Team's merchandise, which proved popular! We spoke to lots of people interested in finding out more about stomas, as well as having some great conversations with ostomates too. We appreciated having two of our sponsors: SecuriCare, and Coloplast, join us for the day.

Just as we hoped, the event generated lots of media coverage. We featured on BBC Look North, Capital Radio, Heart Radio, BBC Radio Leeds, and BBC Radio Lancashire.

Team captain Tom Kaye was interviewed on BBC Look North: "I've played from a junior up to the point where I've had issues and have a colostomy bag on. I've met some of my best friends through Rugby League: the community aspect of it, friendship, teamwork."

Captain of BARA, Dr Ikram Butt, described the event as: "an example of bringing these diverse communities together and having fun in a family-friendly environment."

On the pitch a hard-fought game between our boys and girls and BARA ended honours even in a 16-16 draw.

A huge thank you to Batley Bulldogs, the Batley Sporting Foundation, and Kim Leadbeater MP. All are proving to be wonderful friends of both our Rugby League team and our charity as a whole. Their support is really making a difference for us.

Colostomy UK

CityDietitians

dear dietitian

Pooja Dhir
Specialist Dietitan, City Dietitians
Instagram @dietitian_poojadhir
Email- pooja@citydietitians.co.uk

Stoma and B12 Deficiency

Maintaining optimal nutrition is crucial for people with a stoma. One essential nutrient to focus on is vitamin B12. Since the body's ability to absorb B12 may be compromised after stoma surgery (depending on the type of surgery and how much bowel is left), it is important to ensure an adequate intake of vitamin and mineral levels.

What is B12 deficiency?

A B12 deficiency occurs when your body doesn't have enough vitamin B12 to function properly. Vitamin B12 is an essential nutrient that plays a crucial role in various bodily functions, including nerve function, red blood cell production, and DNA synthesis. When you have a deficiency, it can lead to various health issues and symptoms. There are different causes of vitamin B12 deficiency. To establish the cause and treatment, blood tests will be needed. If levels are low, normally a supplement will be trialled, and levels monitored. If levels increase, diet may be the likely cause. You may be advised to make some dietary changes or to take a supplement/injection.

What are the symptoms of B12 deficiency?

- Fatigue, weakness and a feeling of low energy - this may result in finding it difficult to perform daily activities.
- Nerve problems such as tingling/numbness in hands and feet.
- Digestive issues such as reduced appetite and weight loss.
- Anaemia (megaloblastic) which causes pale skin, shortness of breath and dizziness.
- Neurological symptoms such as memory loss and 'brain fog'.

Individuals with a stoma, especially those who have undergone surgical removal of the terminal ileum (the last part of the small intestine), are at an increased risk of developing a B12 deficiency due to the absorption site of B12 being in the ileum. If you experience these symptoms or suspect a B12 deficiency, it is important to consult with your healthcare professional for a diagnosis. They can perform a blood test to measure your B12 levels and determine the appropriate treatment, which may include dietary changes or B12 supplementation.

How to increase B12 in your diet

- Meat (chicken, beef, lamb, duck, pork, liver pate).
- Fish such as cod, tuna, sardines, salmon, mackerel.
- Milk and dairy such as eggs, cheese, milk.

See the table below for further examples.

Food sources	Serving size (g)	Vit B12 (mcg)
Liver (Beef)	85	71.2
Trout	85	4.2
Salmon	85	3.8
Tuna	85	1.9
Beef (Lean cuts)	85	1.2
Chicken	85	0.2
Eggs	50	0.6
Milk (Cow's milk)	240	1.2
Yogurt (Plain)	245	1.4
Cheese	28	0.4

Vegetarians and vegans, due to their dietary choices, are at an increased risk of developing a vitamin B12 deficiency. Vitamin B12 is primarily found in animal-derived foods, making it challenging for people following a strict vegetarian or vegan diet to obtain sufficient amounts. Plant based sources are generally low in vitamin B12. If you do follow these diets it is important to include fortified plant based milk (soy, almond oat), fortified breakfast cereals, and fortified nutritional yeast in your diet and consider supplementation with B12 tablets depending on the level of dietary exclusion. You should also check the labels of products to ensure they are fortified too!

Treatment and monitoring

If levels remain low, you might have difficulties absorbing vitamin B12. You should then be offered a course of vitamin B12 injections to build up levels and have a follow up blood test. It is likely this treatment may be lifelong and will require frequent blood tests.

Conclusion

Maintaining adequate vitamin B12 levels is crucial for individuals with a stoma. By understanding the challenges associated with B12 absorption, identifying dietary sources, and considering appropriate supplementation options, you can optimise your B12 intake and prevent deficiencies. Regular monitoring of B12 levels and close collaboration with healthcare professionals are essential for long-term well-being.

If you are concerned about any symptoms you may be experiencing or any issues with your stoma, reach out to your dietitian for support and/or contact us at **pooja@citydietitians.co.uk**.

THE 7K STEP CHALLENGE

Step UP FOR STOMAS

This year's challenge is to complete 7,000 steps a day for 37 days, starting on Friday 1st September and finishing on Saturday 7th October, which is Stoma Aware Day!

You can walk, run, jog, skip, dance, climb or even hop those 7,000 steps each day. It really doesn't matter! You can do them on your own, or as part of a team and share the steps between you.

How your fundraising helps

Your fundraising efforts enable us to support thousands of people round the UK before and after their stoma surgery. Thanks to people like you, we will be able to continue providing our 24-hour Stoma Helpline, our one-to-one befriending service, our private Facebook group and Tidings magazine. We can also continue producing our wide range of support literature, running Care Workshops and bespoke activities through our Active Ostomates programme!

> **"While I was in hospital, I started looking at social media for support … I found the Facebook Page Colostomy UK Support group and immediately found a great network of people"**

> **"Colostomy UK was there for me when I was recovering from my stoma surgery...the charity helped me to get my confidence back so I could return to work and socialising"**

Register today at **ColostomyUK.org/get-involved/step-up-for-stomas**

Kickstart your fundraising!

Whether you're walking, running, jogging, skipping, rolling or hopping your way to 7k a day steps, the money you raise will help us to keep on supporting ostomates and those who care for people with stomas.

You can set up your Step Up for Stomas fundraising page on Just Giving or Facebook - you can also use the sponsorship form overleaf (page 28).

JustGiving

Visit: justgiving.com/campaign/stepupforstomas7k

facebook

Visit: facebook.com/colostomyuk

There is no need to send us your step count. But tracking your progress using your phone, smartwatch, or other device, or linking your strava app to your Just Giving fundraising page, is a great way to keep your family and friends up to date with how you are doing.

Fundraising Top Tips

Set a target

Fundraising pages with a fundraising target, are generally more successful than those without. We recommend setting an initial target. If you meet this target before completing the challenge, you can of course increase it! This will give you some great news to share with family, friends and work colleagues to inspire them to donate.

Seed donations to get the ball rolling

Fundraising pages with a few donations already on them give potential donors confidence and help you achieve further donations. If you can afford to, maybe think about putting an initial donation on your page and approaching two or three people personally to ask for donations, before sharing your page with the wider public.

Use social media

Tell people what you are doing and don't forget to tag us in! Each share could encourage another person to donate, so post on Facebook, Twitter and Instagram and put your fundraising link in your page's bio or status. Tell people why raising money for Colostomy UK is important to you and keep your pages updated so people can follow your journey.

You can download our social media graphics from our website.

Visit: **ColostomyUK.org/get-involved/step-up-for-stomas**

Match funding

If you are an employee, then why not ask your company for support, as it can be a tremendous boost to your fundraising efforts. Some companies offer to match charity donations raised by their employees up to a certain level, either with a one-off amount or matching everything you raise.

Giftaid it

Because we are a self-funding organisation, every penny we raise really matters, so please remind your sponsors that if they are a UK taxpayer, to tick the gift aid box on your online donations page or sponsor form. For every £1 raised, we get 25 pence back from HMRC, which means your efforts go even further.

giftaid it

Get your Challenge T-shirt

Don't forget to order your Step Up for Stomas branded t-shirt today, so you can promote the fantastic challenge you are undertaking!

T-shirts are available in sizes XS – XXL and are just £12 plus postage & packaging.

Place your order at:
ColostomyUK.bigcartel.com

T-shirt reverse (above)

Frequently asked questions

Do I need to prove I've achieved my challenge?

This is your challenge, so you don't need to send us proof that you've reached your goal. However, we recommend updating your progress on your fundraising and social media pages, so your friends and family know how you're getting on.

What happens if I miss a day?

Don't worry if you miss a day, it's up to you how you complete your steps. You could always make up the steps across the next week!

What happens if I don't hit my step goal?

We understand if you're not able to hit your step count. Don't panic if you need to put your challenge on hold, or you're unable to complete your daily steps. You can simply resume the challenge once you're able to or team up with friends, family or colleagues to complete your steps together. We can't thank you enough for your support.

Are there other ways to complete the challenge?

Yes, you could swim or cycle the challenge for example, but just remember to convert your distance into steps.

I use a wheelchair, how can I count my steps?

If you use a wheelchair, you can track your distance and convert it into steps.

Sign up today, and we can make this year's Step Up for Stomas the best year ever!

Step UP FOR STOMAS

THE 7K STEP CHALLENGE

Sponsorship Form

Participants Name: ______________________________ Participants Email: ______________________________

Participants Phone No: ______________________________ Date of event: ___/___/____ Sheet No: ____ of ____

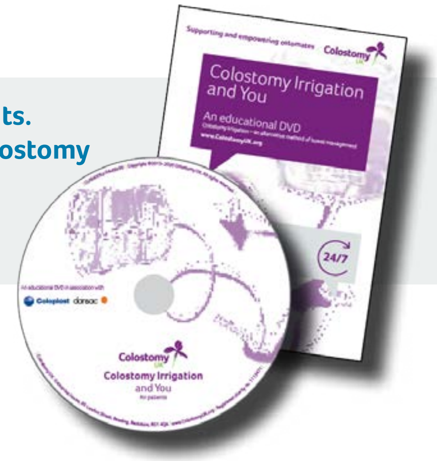
We wish you every success with your fundraising activity. Please remember to return this form to our office with any money raised, otherwise we will be unable to claim Gift Aid. The donors full name, address and postcode are needed in order for us to claim Gift Aid. You have a legal responsibility to ensure all sponsor money is paid to *Colostomy UK*. Please print another copy of this form and number it, if you need additional pages. Cheques should be made payable to *Colostomy UK*. Thank you for your support.

Title	First Name	Last Name	Address	Postcode	Amount	Paid	Gift Aid*
MR	JOHN	SMITH	1 EXAMPLE ROAD, EXAMPLE STREET, READING, BERKS	AB1 2AB	£25.00	YES	YES

*I want to Gift Aid my donation and any donations I make in the future or have made to Colostomy UK in the past four years. I am a UK tax payer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of the Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference (currently 25p for every £1 donated).

Please return completed form(s) to: Colostomy UK, 100 Berkshire Place, Winnersh, Wokingham, Berkshire, RG41 5RD

Colostomy Irrigation and You DVD



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

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

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

Colostomy UK, 100 Berkshire Place, Winnersh, RG41 5RD

Title: ______________________________

Name: ______________________________

Address: ______________________________

____

______________ Postcode: __________

Tel: ______________________________

Email: ______________________________

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

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

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

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

Signed: ______________ Date: ______________

Also available to purchase online at: **www.ColostomyUK.bigcartel.com**

Please allow 30 days for delivery.

Colostomy UK, 100 Berkshire Place, Winnersh, RG41 5RD | Charity No. 1113471 | VAT No. 917079312

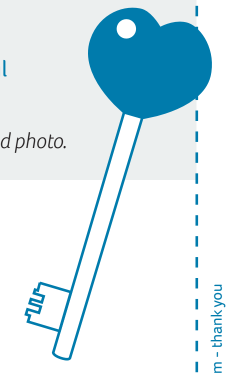
Please cut along the dotted line and return to the address on this form - thank you

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

Ensure you always have access to a toilet by purchasing a Radar Key and Photo ID card. Through the National Key Scheme, Radar keys open the doors to over 9,000 accessible toilets in the UK in places like shopping centres, pubs, cafés and department stores.

A Colostomy UK Photo ID card, which is endorsed by Disability Rights UK (and displays their logo), can be helpful if you need to use accessible facilities urgently, particularly if they aren't part of the National Key Scheme.

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



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

Title: ______________________________ Address: ______________________________

Name: ______________________________ ______________________________

Tel: ______________________________ ______________________________

Email: ______________________________ Postcode: ______________________________

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

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

Please **tick** as appropriate:

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

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

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

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

Menopause and Me – Sue Rogers

BY JILLIAN MATTHEW

Sue Rogers was diagnosed with stage 4 rectal cancer in March 2016 at age 49. She now has a permanent colostomy (Bertha) after a journey of radiotherapy, chemotherapy, sepsis and two lots of major surgery. Sue says the 'new normal' for her is a very different one, not only physically, but psychologically too.

"I have worked hard to get myself as good as I can. I work on my emotional wellbeing daily and I am fortunate to have an amazing husband Pete by my side."

Sue was shocked to find out she had rectal cancer as she hadn't experienced the usual symptoms, apart from one brief bout of abdominal pain and passing blood when she was on holiday in Turkey. She had put this down to eating too many nuts and goji berries bought at a market. Sue had gone to see her GP in early 2016 about a cough and when she mentioned feeling unwell on holiday, she was referred for a colonoscopy. Five weeks later when she had the procedure the doctor started to talk to her about cancer, assuming she already knew. It turned out that Sue had a large tumour which had grown outside of the wall of the rectum and spanned from the front to the back of her abdomen. This is rare, usually a tumour would grow inside the rectum, and was why Sue didn't experience symptoms.

The menopause is now giving Sue a whole new challenge. Many of the symptoms are reminders of her cancer treatment. She finds her brain wanting to pull back into the trauma of past events and 'trick' her that she might be unwell. Therefore she says she has to be so mindful to continue to train her brain that this is not that journey, that it is the menopause which thousands of women are going through and that she is OK.

"Being a lady of a certain age the menopause has entered my life with a BOOM! My poor husband is like 'what is going on now?' And I say I know it is minus three outside but I need the window open. No you don't need the heating on its boiling in here. Why are you looking at me like that…? Many jokes and much laughter have been the butt of the menopause but then it happens to me and it is no joke!"

Sue didn't realise she was menopausal until she had a chance conversation with a work colleague who was having similar symptoms, which led her to discussing it with her GP. Initially she had put the exhaustion down to the stress of work. Sue has been suffering fatigue, fogginess, a change to her skin, itching, and at times she doesn't want to go anywhere. The underlying anxious thoughts and feelings Sue has also been experiencing, what she often calls 'rising panic', are very similar to how she felt going through cancer treatment: the brain fog, not knowing what the next word is she wants to say; the night time game of 'quilt on quilt off' and spending a lot of time looking for lightweight and cool nightwear. All are similar to how she felt when having chemotherapy. It is also having an impact on her husband. He saw how she was through her cancer treatment, and it is triggering for both of them.

Sue has been experiencing symptoms that are affecting her stoma, including skin changes affecting how well her bags stick. She said the menopause is being talked about more and more and this can only be good, however the difference for those who have been through cancer can be that they are not able to access the medical support that others can. Sue's skin is so thin from radiotherapy that many creams are not suitable. Sue was advised by her GP that she couldn't have hormone replacement therapy (HRT) because of her cancer but she thinks they are taking a blanket approach and not looking at her individual circumstances. She feels a 10-minute appointment is not long enough to look at the 'whole me' and work out what's best for her. She has tried to find more information about taking HRT for women with a history of bowel cancer but there has been little research carried out in this area. Sue has seen how much HRT helps other people and it upsets her that this has seemingly been ruled out for her, although she is going to seek further medical advice to see if she can be prescribed HRT.

Meanwhile Sue is doing what she can to navigate her way through menopause. She takes turmeric to try to alleviate joint pains and uses cognitive behaviour therapy to manage anxiety. Sue works for a UK-wide charity and has helped to set up a support network and menopause cafés for colleagues. She advises other people going through menopause that you are not on your own and to seek out a peer to discuss it with. She includes men in this too, as they are also affected by what their partners are experiencing.

Sue remembers feeling vulnerable during her cancer treatment and menopause has knocked her confidence and given her imposter syndrome. She said the trauma of having cancer changes your thinking, makes you think the worst and menopause retraumatises you and brings another layer of not being well again. She said you have to take a hold of yourself and think about the probability – that it's unlikely to be cancer again. For anyone in a similar situation, Sue said it's being able to say to yourself:

> **"It's not cancer, it's going to be ok, you will come out of the other side, go and talk to someone, menopause is different".**

Information about the menopause, menopausal symptoms and treatment options can be found at:

www.menopausematters.co.uk

Recycle and Raise Money for Colostomy UK

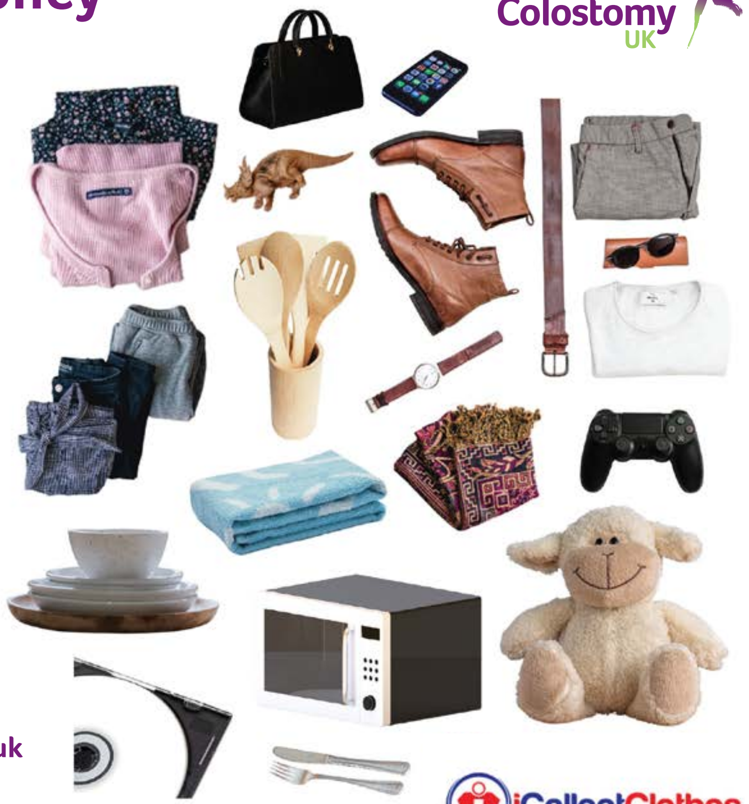
We've teamed up with **icollectclothes** to offer you a hassle-free way to clear your home of unwanted items and raise money.

icollectclothes will pick up your unwanted clothing, shoes, bedding, towels, curtains, accessories (bags, belts, hats, scarves) books, DVDs, CDs, soft toys, electronics and even small domestic appliances and convert them into a donation for Colostomy UK.

Help us to continue supporting and empowering Ostomates.

If you live in London and the South, The Midlands, North West or North East, it's easy to book a collection online at:
icollectclothes.co.uk/donate/colostomy-uk

In other areas, please call: 0344 879 4417.



iCollectClothes

Support at your fingertips

Why not join our Private Facebook Group?

- For Ostomates, their family and friends.
- Join our growing community of over 11,000 members.
- Offering you a safe and supportive place to shares stories and learn from others.
- Meet new people from the comfort of home.
- It's free and easy to join!

Simply search on Facebook for *'Colostomy UK Support Group'* and click the join button.

Research Round up

Dr Benjamin Saunders
Senior Lecturer in Health Research, Keele University

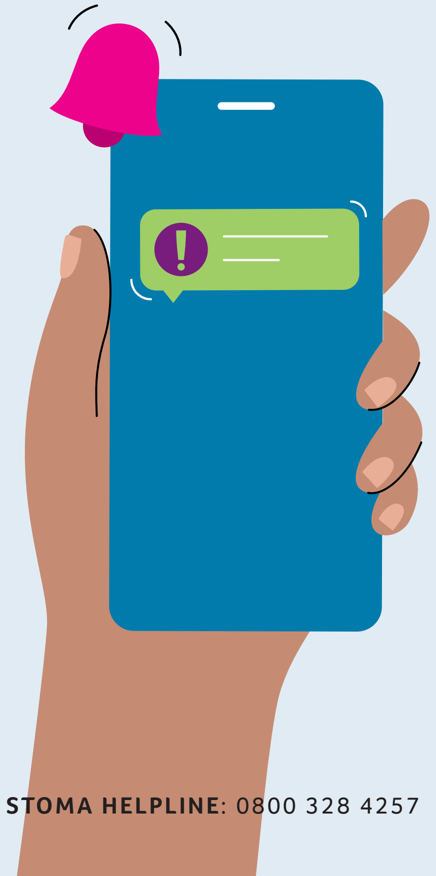
Ben has been carrying out research that aims to improve the lives of ostomates for a number of years.

In this edition, I continue my round up of research that's been published on stoma care and experiences over recent months. I'll be discussing four studies, which I hope you'll find interesting and thought-provoking.

STUDY 1

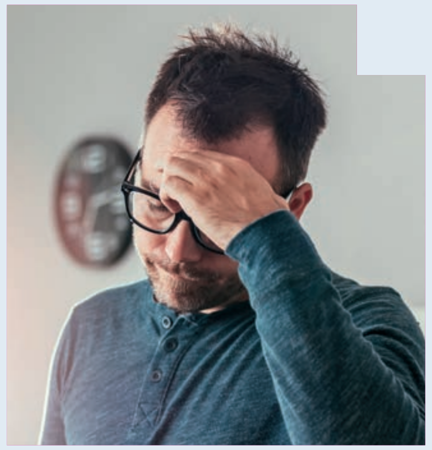
The first study focuses on an issue many ostomates will relate to: the fear of stoma bag leaks.

A team of researchers in the UK, USA and Denmark, tested a new innovation – a "digital ostomy leakage notification system". This is a medical sensor device that attaches to an ostomy baseplate and sends messages to a smartphone App via Bluetooth (all very technical!). These messages tell the ostomate when they are at risk of getting a leak. The researchers tested whether use of this device could improve the number of leaks that people experience, how much they worry about leaks, and their overall quality of life.



The study took place in Denmark, with 25 people with a colostomy or ileostomy trying out the device for 21 days. This group had all expressed high levels of worry about having stoma bag leaks.

The results showed that, on average, participants experienced 2.8 episodes of leakage onto clothes during the 21 days. When compared to the period before they used the device, this showed an 82% reduction in leaks. Before using the device, 48% of the participants worried about leaks to a 'high' or 'very high' degree, and 44% worried about leaks to 'some' degree. There was a big improvement afterwards, as none of the participants worried about leaks to a 'very high' degree and just over 4% worried to a 'high' degree. Most participants (70%) worried to a 'low' or 'very low' degree. After using the device participants also felt significantly better in terms of the emotional impact of leaks than they had prior to using it.



These results are very promising, particularly for ostomates who struggle with leaks or worry a lot about this. What is not known yet is how useful this device will be for people who don't have leaks as regularly or who don't have high levels of worry. The research team plan to test this leakage notification system in larger and more diverse populations, so it will be exciting to see what they find. I'll make sure to update you on this research in future editions.

STUDY 2

The second study I've chosen focuses on a topic that many of us may find it difficult to talk about: sex after stoma surgery.

Researchers in Poland conducted a review of published research studies that have investigated this topic, to try to understand the quality of stoma patients' sex lives.

They included studies from anywhere in the world over the past five years, but excluded articles not written in English. After screening several thousand articles, 13 were included in the final review. Studies were conducted in Europe, Asia and South America, with one of these being based in the UK. Six of the studies focused on people with a colostomy, one focused on those with an ileostomy, and six included people with either.

All of the studies in the review found that undergoing stoma surgery had a negative impact on the quality of people's sex lives. Reasons for this included sexual dysfunctions (in relation to certain types of surgery); changes in body image; lack of partner acceptance; decreased sexual satisfaction; lack of sexual education; and problems related to stoma hygiene.

Some studies found that when having sex, individuals felt anxiety that they might have a bag leak, or that there could be unpleasant smells and noises. These fears meant people didn't enjoy sexual intercourse, and as a result, some reported having lower self-esteem.

So far, these findings paint a picture of doom and gloom; however, there were also some more positive findings from the review. Support from spouses or partners was found to be essential, and ostomates who had strong bonds with their partners returned to sexual activity more easily and led happier intimate lives. Many people said that the process of adapting to a stoma made their relationship stronger.

The researchers highlight the responsibility of the medical team to support people in adapting to their stoma, which includes talking about sex. They acknowledge, though, that many people will feel uncomfortable raising this with their stoma nurse. One thing that I can add to this based on my own research is that health professionals often don't feel comfortable raising this either, so it may be that support is needed for both ostomates and professionals. I'm currently leading a research study called the Stoma Support Study, in which my team are developing an online resource to support younger people after stoma surgery, as well as a training package for health professionals (in collaboration with Colostomy UK). Advice and support about sex and intimacy is one of the key areas we're focusing on, so hopefully we can do something to help people who are struggling with this in the future. I'll share more with you about the Stoma Support Study in a future edition!

STUDY 3

The third study I've picked out looked at the dietary habits of people with an ileostomy.

A UK-based research team (led by a registered dietitian) recruited 44 ostomates from NHS hospitals. Seventeen had a newly formed ileostomy (6–10 weeks post-surgery); 15 had an 'established' ileostomy (at least 12 months post-surgery); and 12 had a stoma reversal. Participants completed a questionnaire about their food habits and were asked to estimate how often they had experienced certain symptoms during the previous week, for example pain or gas. They were also asked about their dietary intake, using either an online diet recall programme or a three-day food diary.

Out of the 17 participants with a newly formed ileostomy, 15 reported avoiding foods and drinks because they were advised to do so, as well as due to increased gas. Most avoided fruit and vegetables, but some also avoided nuts and mushrooms.

Thirteen participants with an established ileostomy reported avoiding foods or drinks to control symptoms. The most common reason given was visibility of the stoma bag, or that they had been advised to avoid them. Participants whose ileostomy had been reversed reported higher fruit and vegetable intake than the other two groups (3.2 portions per day on average), which is similar to the general population.

Overall, for all groups (newly formed ileostomy, established ileostomy and reversal), the reported intakes for nutrients were similar to the general adult population, except for fibre intake, which was lower in all three groups.

The most common reason for avoiding a food was that participants had been advised to avoid it. However, it was found that for most people with ileostomy only a few foods caused problems (nuts, mushrooms, sweetcorn and fruit and vegetable skins appeared to be most problematic).

Based on these findings, the researchers recommend that people with an ileostomy can eat a varied diet, and after the initial healing period, foods should not be automatically excluded unless they cause problems after being reintroduced. They conclude that dietary advice should be individualised based on the person's needs, and long lists of food to avoid should not be handed out to everybody as standard.

These findings may be encouraging to people with a recent ileostomy who are just beginning to find their feet in terms of what they can and can't eat. The advice received about diet appears key to people's decisions about which foods to avoid, so it will be interesting to compare these findings to the final study I'll share with you, which was carried out by the same research team.

STUDY 4

In this study, interviews were carried out with 21 health professionals to gain their views on dietary advice for people with an ileostomy. This included five stoma nurses, five dietitians, five colorectal surgeons, four colorectal specialist nurses, one IBD nurse, and one gastroenterologist, recruited from three hospitals in South-West England.

Most of the health professionals felt that patients need to find a personal balance that works for them, through 'trial and error'. They said that they give their patients general guidance on gradually reintroducing higher fibre and other potentially problematic foods but encourage their patients to take ownership of their diet. None of the professionals described advising patients to follow a very restrictive diet long-term.

In terms of how dietary advice is given, it was found that surgeons often communicated in a 'paternalistic' way, through telling patients what they should or shouldn't eat and drink. In contrast, stoma nurses and dietitians said they 'compromise' with patients and like to include them in decisions about their diet.

Many professionals said they lacked confidence in giving dietary advice, and the researchers suggest that better communication between different health professionals could help to increase knowledge and understanding of individual patients' dietary needs.

When interpreting these study findings, it's important to note that all of the participants worked in South-West England, so it was not possible to explore any regional differences in health professionals' views. Overall, though, it seems that encouraging professionals to work more closely with one another, and to take a personalised approach to advice on diet, is a positive forward direction for this aspect of stoma care.

Brady RRW, Fellows J, Meisner S, Olsen JK, Vestergaard M & Ajslev TA (2023) A pilot study of a digital ostomy leakage notification system: impact on worry and quality of life. British Journal of Nursing, 32(6): S4-12.

England C, Mitchell A & Atkinson C (2023) Diet After Ileostomy Study: an observational study describing dietary intake and stoma-related symptoms in people with an ileostomy. Journal of Human Nutrition and Dietetics. DOI: 10.1111/jhn.13169.

Mitchell A, Herbert G, England C, Atkinson C & Searle A (2023) Healthcare professionals' perspectives on dietary advice provided to people with an ileostomy. Journal of Human Nutrition and Dietetics, 36: 716–728.

Paszynska W, Zborowska K, Czajkowska M & Skrzypulec-Plinta V (2023) Quality of Sex Life in Intestinal Stoma Patients—A Literature Review. International Journal of Environmental Research and Public Health, 20(3): 2660.

Colostomy UK news

Libby Herbert
CEO
Libby.Herbert@ColostomyUK.org

Welcome to the TEAM

Lindsay Walrond

Lindsay joined us in June as our new Fundraising Manager, bringing with her 20+ years' experience of fundraising in the charity sector.

This includes specialising in generating funds for health-focused organisations from charitable trusts to foundations, which is of course very relevant to Colostomy UK!

When not out beating the fundraising drum, Lindsay can be found trying to improve the family's 'retro' home on the south coast, walking her chocolate Labrador Monty, and pursuing a random selection of pastimes, from cross-stitch to keyboard.

Improving the Stadium Experience

Back in May we were thrilled to be invited to give a presentation about Colostomy UK at the Level Playing Field and the English Football League's (EFL) Access Officer's conference. The Royal National Institute of Blind People and Tourettes Action UK also gave talks.

Level Playing Field and the EFL are working hard together to make football stadiums more inclusive. It was a great event, where we got an update on the adjustments that are being made to improve the stadium experience for fans and learned about the roles and achievements of disability access officers from football clubs across England. What's especially good is that they are consulting with charities like us, who are involved in both raising awareness of hidden conditions and supporting people with them. This has positive implications for both the adjustments they make to their facilities and also the training their customer-facing staff receive.

Our informal partnership with Level Playing Field has led to a number of football clubs making their toilets stoma friendly. We hope to announce more soon!

Airport Update

In June our CEO Libby Herbert was asked to become a member of Gatwick Airport's Independent Gatwick Accessibility Panel, which first convened in 2019.

The panel's purpose is to bring together a small but inclusive and independent panel of experts to advise on the travel needs of disabled people. The panel takes a strategic view of all things related to accessibility provision at Gatwick and identifies opportunities for influencing change at the airport and for collaboration with airlines.

As well as Gatwick we are now involved in nine airport accessibility forums (Manchester, Birmingham, London Luton, Stansted, Heathrow, Bournemouth, Cornwall, and Cardiff) and Libby also sits on the Civil Aviation's Access to Travel forum.

Our work with aviation is leading to collaboration with other organisations, such as Transport for London, Network Rail and Southeastern Railways. We have also had an initial discussion with the Department for Transport too.

Colostomy UK

volunteers

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

Right from our beginnings in the 1960s volunteers have been at the heart of our charity. Today, as Trustees they oversee what we do, while other volunteers play a central role in the delivery of our many services. Even the words you are reading now will have been proofread by a volunteer.

We have never strayed from our founding belief that having been through stoma surgery and adjusted to life with a stoma afterwards puts you in a unique position to support and help other ostomates. With this in mind, it is not surprising that we have developed as a volunteer-centred charity. Annual Volunteers' Week (1 - 7 June) therefore always figures prominently in the Colostomy UK calendar. It's our chance to celebrate our roots and say 'Thank You' to our volunteers, past and present.

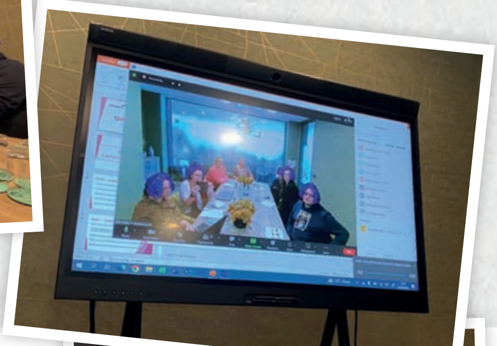
This year, as well as using social media and our website to recognise our volunteers and talk about the positive impact they have on people's lives, we had a bit of fun. This took the form of a virtual coffee morning and quiz, held via Zoom.

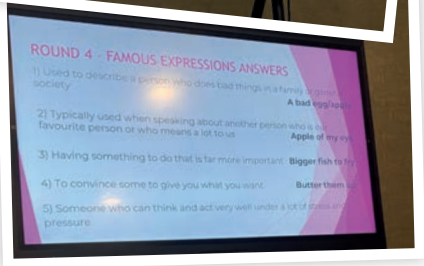
Members of the office team were the quiz masters, each donning a purple wig (in honour of Colostomy UK's purple Iris logo) and taking it in turns to read the questions.

Lots of volunteers were able to take part and, once they had got over the strange sight of ten people with purple hair, proceeded with the serious business of quizzing. The prize (a Colostomy UK Hoodie) went to Vanessa, who has been a volunteer with us for well over a decade.

See how you do with this selection of the questions from the general knowledge round. You will find the answers in small print at the bottom of the page. No peeking!

1. Which country has the highest life expectancy?
2. What herb is used to make pesto?
3. Which came first: McDonald's or KFC?
4. What is a group of pandas called?
5. What is the nation's favourite biscuit according to YouGov?
6. Where would you be if you were standing on the Spanish Steps?
7. After a classification challenge in 1991 for the purposes of VAT, did the courts decide that a Jaffa Cake was indeed a cake or a biscuit?





ROUND 4 - FAMOUS EXPRESSIONS ANSWERS

1) Used to describe a person who does bad things in a family or [illegible] society — A bad egg/apple

2) Typically used when speaking about another person who is our favourite person or who means a lot to us — Apple of my eye

3) Having something to do that is far more important — Bigger fish to fry

4) To convince some to give you what you want — Butter them up

5) Someone who can think and act very well under a lot of stress and pressure

Interested in volunteering?

If you ask someone why they volunteered with us, they will invariably tell you that they did so because they wanted to use their experiences of surgery and life with a stoma to help others.

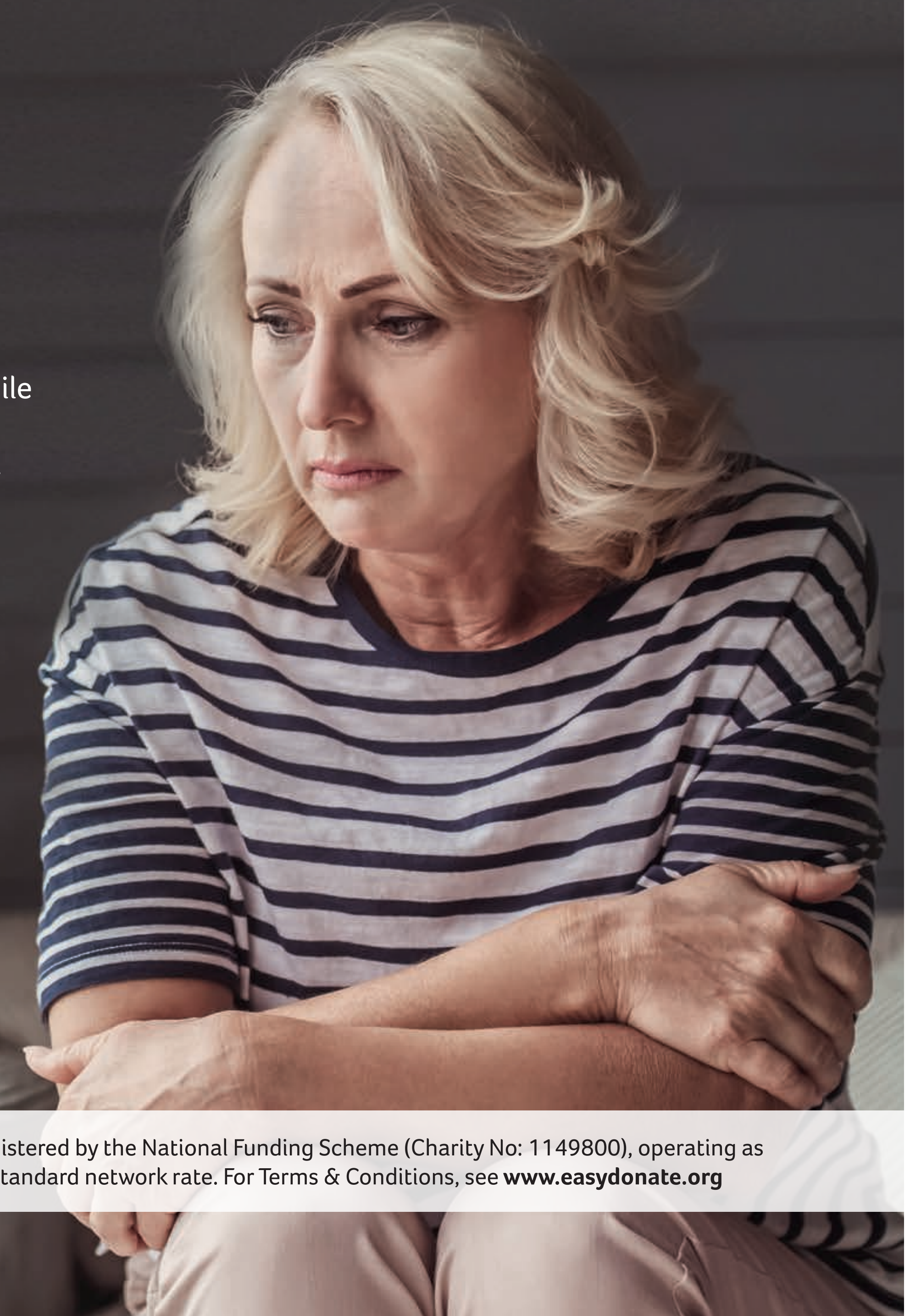
If you would like to know more about becoming a Colostomy UK volunteer, then please drop us an email to: **volunteer@ColostomyUK.org**. The application process is straight-forward, and you will receive full training.

Answers: 1. Hong Kong. 2. Basil. 3. McDonald's. 4. An embarrassment. 5.Milk Chocolate Digestive. 6. Rome. 7. A cake.

Colostomy UK

No one should face stoma surgery alone.

Make sure they don't. Donate now.



Choose your donation method:
Cheque, standing order or direct debit: please see the donation form on pages 41-42.

Debit or credit card:
visit www.colostomyuk.org/donate
or call us on 0118 939 1537

By text: To donate £5 on your mobile device please text TCUK to 70970.
To donate £10 text TCUK to 70191.

Or scan me to donate today

Thank you for your support.

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

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

Please support Colostomy UK

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

Colostomy UK

My Details (Please complete in **BLOCK CAPITALS**)

Title*: First name*: Last name*:
Address*:
Postcode*: Phone Number:
Email*: Date of birth:
Gender: ☐ Male ☐ Female ☐ Other, please specify:

If you are new to **Colostomy UK**, how did you hear about us?
Are you: ☐ An ostomate ☐ A carer ☐ A healthcare professional ☐ Family or friend
☐ Other, please specify: Stoma type: ☐ Colostomy ☐ Ileostomy ☐ Urostomy
Date of surgery: Reason for surgery:

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

You are in control of the information you receive and can change your options or unsubscribe at any time. I would like to be kept informed and receive (please select and tick the box):

☐ Monthly **Colostomy UK** support e–newsletters
☐ Post from carefully selected third parties (eg about open days or offers)
☐ Emails from carefully selected third parties (eg about open days or offers)

Any other details you would like to share with us

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

My one-off donation

☐ £25 ☐ £30 ☐ £50
☐ Other amount (please state) £
☐ I enclose a cheque or postal order made payable to **Colostomy UK**
☐ Please debit my Visa/Mastercard/Maestro Card with the amount specified

Card number *(Maestro only)*

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

Signed Date D D M M Y Y

giftaid it **Thank you for your gift** T71

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

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

Signed: Date: / / 2023

Please fill in this form to make a donation. Check your details are correct, then return the completed form by post to: **Colostomy UK, 100 Berkshire Place, Winnersh, Wokingham, Berkshire, RG41 5RD.**
Telephone: **0118 939 1537** if you have any queries.

Registered Charity No: 1113471

Registered with FUNDRAISING REGULATOR

Charity Name:

Colostomy UK

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

Name and full postal address of your Bank or Building Society

To: The Manager ....

Bank/Building Society ....

Address ....

....

.... *Postcode* ....

Name(s) of Account Holder(s)

....

....

Bank/Building Society account number

☐☐☐☐☐☐☐☐

Branch Sort Code

☐☐☐☐☐☐

Service User Number

6	9	1	2	1	3

CAF, Kings Hill, West Malling, Kent, ME19 4TA

Instruction to your Bank or Building Society

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

Signature(s)

....

....

Date (DD/MM/YYYY) ....

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

This is not part of the Instruction to your Bank or Building Society

My Details

Title

☐ *Mr* ☐ *Mrs* ☐ *Ms* ☐ *Other (please specify)*

Name

....

....

Address

....

....

....

.... *Postcode* ....

Donation Details

I would like to make a regular donation of £ ....

☐ *Monthly* ☐ *Quarterly* ☐ *Half Yearly*

☐ *Annually Commencing*

01 / ☐☐ / ☐☐☐☐ *OR*
15 / ☐☐ / ☐☐☐☐

Gift Aid Declaration

Please Gift Aid this donation and any donations I make in the future or have made in the past 4 years. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year, it is my responsibility to pay any difference. Please notify us if you want to cancel this declaration, change your name or home address or if you no longer pay sufficient tax on your income and/or capital gains.

☐ *Tick to apply*

This guarantee should be detached and retained by the Payer

The Direct Debit Guarantee

- This guarantee is offered by all Banks and Building Societies that accept instructions to pay Direct Debits
- If there are any changes to the amount, date or frequency of your Direct Debit, Charities Aid Foundation will notify you ten working days in advance of your account being debited or
- If an error is made in the payment of your Direct Debit, by Charities Aid Foundation or your Bank or Building Society, you are entitled to a full and immediate refund of the amount paid from your bank or building society - If you receive a refund you are not entitled to, you must pay it back when Charities Aid Foundation asks you to
- You can cancel a Direct Debit at any time b y writing to your Bank or Building Society. Written confirmation may be required. Please also send a copy of your letter to us.

Giovanni Cinque
Marketing & Campaigns Manager
GetInvolved@ColostomyUK.org

#ActiveOstomates

active ostomates®

Are you ready to take the plunge?

Before the pandemic, we held swim sessions across the UK. This involved hiring the entire pool and changing rooms to create a private space for participants.

We're delighted to announce that our Active Ostomates Swims are returning this autumn with sessions in Windsor and Heywood:

SEPT 2 Windsor Leisure Centre

Clewer Mead, Stovell Road, Windsor, Berkshire SL4 5JB. 6.30pm to 7.30pm.

OCT 14 Heywood Sports Village

West Starkey Street, Heywood OL10 4TW. 5pm to 6pm.

Both are free to attend, and you can bring a friend or family member too.

To confirm your attendance or find out more visit **ColostomyUK.org/active-ostomates/swimming**

If you're thinking of attending or just going to your local pool, classified British para-swimmer and ostomate Tasha Critchley's top tips should boost your confidence.

Find swimwear you are comfortable in

If you feel comfortable in your swimwear, you will feel confident getting into the pool. Bright colours and patterned swimwear tend to make people feel more confident as it makes any outline of a bag less visible.

Try your swimwear on in front of a mirror

If you are still anxious, try your swimwear on in the mirror. This should make you realise that your bag won't be visible to other people.

Does your bag need a filter cover?

Before you go swimming, check if your bag needs a filter cover. If it does, these will come in the box your bags arrive in. They are circle stickers that fit over the filter at the top of your bag. It prevents any water from entering the bag whilst you are in the pool.

Drying/changing your bag after swimming

If you can use a disabled changing room when you are getting dressed after your swim. More often than not, these will have a hand dryer or a hair dryer. Using this for a minute or two to dry your bag will allow you to keep it on if it is empty. If the bag needs changing, then just perform the change as you would at home, then pop the bag into the nappy bin.

Enjoy being in the water

Last but by no means least, enjoy your time in the water. Be proud of yourself for overcoming such a big obstacle. Just remember that nobody will see your bag so there is no need to be worried.

You can find out more about all of our Active Ostomates activities including our virtual Yoga, Chair Yoga, Pilates, Zumba, and Mindfulness & Meditation classes, plus lots of hints and tips on getting moving, by visiting **ColostomyUK.org/active-ostomates**.

Your Letters and Emails

Editor's note:

Thank you to everyone who has been in touch since the last edition. Here is a selection from the mailbox. Please keep those letters and emails coming.

As one reader reminds us iCollectClothes doesn't just collect clothes (see p32).

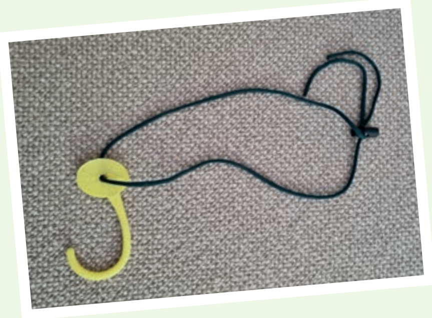
Hello

I thought you might like to know that as a result of the advert in the recent Colostomy UK Tidings magazine I have sent a box of cut-glass decanters to icollectclothes for your benefit. Worth your mentioning the system in future even if the collection firm does not put in an ad.

Regards, David Cunningham Green

Thank you to Mr A J for sending in this tip. It will be familiar to some readers, but not to others!

Mr J uses a simple hook and string arrangement (as pictured in the sample he sent me) to hold up his shirt and vest when changing his bag if he is away from home. The string goes round his neck, with the hook at the bottom.



Editor's note: One reader got in touch after watching the video on YouTube: Flying with a Hidden Disability – Stoma, to tell me about her recent airport and air travel experience. The video was put together by Queen Elizabeth's Foundation for Disabled People and the Civil Aviation Authority and supported by Colostomy UK. This is what she had to say:

Great video. The speaker says exactly how I feel. It's the stress and fear of security which is the issue. Just flown for the first time since Covid. Security were great. Waved through fast track due to the hidden disability lanyard. Had explained I had a medical bag. The lady on security asked what was in it. As soon as I said ostomy products, she smiled and said, any adhesive sprays? There weren't. Coming home I once had the experience that the queue for passport control was massive. My bag had filled but luckily I was able to use the toilet on plane before disembarking, otherwise I wouldn't have made it through. The lanyard gets me through fast-track passport control now. This time we were noticed and waved forward and the way to assistance pointed out. Through passport control in moments. AND Manchester airport Terminal 2 now has toilets every few meters on the walk through to passport control.

With regards to the airline, I realised that there was no guarantee that cabin luggage would be allowed on the plane, depending on space (You know all those people who take the biggest bag possible!), so I rang medical assistance to advise that I was carrying medical equipment. I prefer to have my bags and supplies in hand luggage - I know I've got it. It took a while to get through but was well worth the wait. The lady at Jet2 allocated me a second 10kg hand luggage for medical supplies (it has to be separate from your personal hand luggage). She went through everything, including in resort transfers and booked seats. With Jet2 if you need medical assistance you don't pay for pre-booked seats. I like aisle seats with access to a toilet. All in all, an excellent service from airline and airport staff.

Karen

Dear Editor,

I have had a Colostomy since 2005 and Urostomy since 2007 and mostly we get along reasonably together. I am 80 and have had no further episodes of bowel cancer or secondaries since 2009.

Last year my husband and I flew to Australia to visit our daughter and family in Perth, for Christmas. We have visited Perth many times and, having both a colostomy and a urostomy, I pack double the amount of supplies that I use at home.

We had two lovely weeks baking for Christmas and spending time with grandchildren home from Uni for the long holidays. Then, out of the blue, my husband and I, plus our 20-year-old grandson, became very ill with fever and diarrhoea. Four of the family were fine, three of us were sick. On Christmas Day all we could eat was a small amount of rice with yoghurt but didn't really want anything!

I got worried I was going to run out of colostomy pouches rather quickly, so we immediately contacted the Perth Stoma association before they closed. They didn't have the flushable ones I was using but ordered a box for me from the East Coast at a cost of £50. It had to come about 3, 000 miles and I was told it might take 2-3 weeks by train because of the holiday period. That wasn't much comfort.

Fortunately, our daughter has a social worker friend, who was friends with a stoma nurse in Perth. Because our NHS and Medicare in Australia have a reciprocal agreement, she was able to supply me with a pack of drainable pouches. I had never used drainable bags and took a few days to manage them, but they saved the day.

I managed to get a doctor's appointment over New Year, via our insurance, at a nearby private hospital, and gave a specimen. This showed that we had contracted Campylobacter, a nasty type of food poisoning. We have no idea where it came from. I was prescribed antibiotics so by the time we left Perth on 19 January I was well again, but it felt rather a waste of a holiday. We were so grateful we were with family and not in a hotel.

My advice to people going away for a while is to get hold of a few drainable pouches just in case they might be needed. The last thing we expected was to get such horrible diarrhoea in our daughter's home and it has never happened to me before over 20 years of travelling there. Oh and the ordered pouches arrived the day we left Perth!

Christine Hill

A precautionary tale

Never leave a stoma unattended,
A stoma is a fickle little thing.
For even though you've checked it
And when you least expect it,
Off it goes with just another little 'ping'!

So yes, nice to have an airing,
Just perhaps don't be too daring
Always keep some wipes or tissues somewhere near.
'Cos it will fire up when it may
And make quite a big display
But not one of your choosing though I fear!

So please heed this little warning
For before or after shower
Whether it be night, or early in the morning.
You see, it's not your choice,
You don't really have a voice.
That little pinkie is the one with all the power.

By Christine Wright

We look forward to hearing from you, our readers:

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

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

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

News from Support Groups across the UK

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

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

Tel: **0118 939 1537**
Email: **hello@ColostomyUK.org**

Mid Devon Ostomy Support Group

Last meeting of 2023 Saturday 18 November

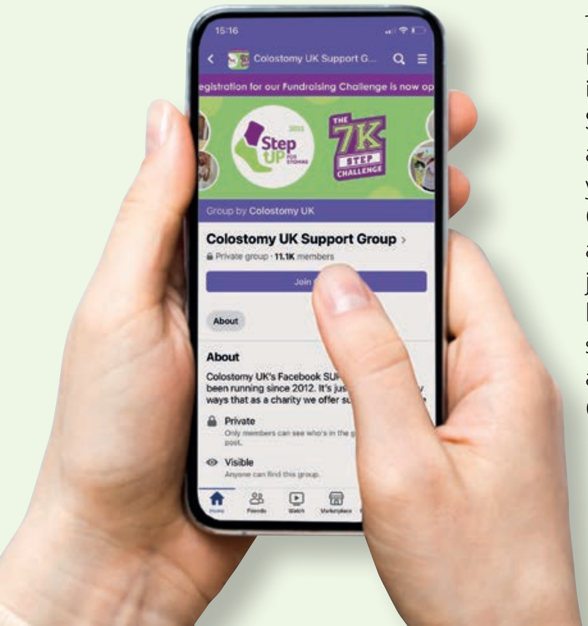
All welcome anyone with any type of stoma. We are an informal friendly group join us for a cuppa, cake and raffle. Hollister, CliniMed and CUI have confirmed attendance. We usually have a stoma nurse from the Royal Devon University Healthcare Hospital Exeter come along as well.

Meeting at the **Boniface Centre, Crediton 2-4pm EX17 2AH**. Car park at rear or easy to get to by bus or train.

For more details, contact Janice on **07923975051** or email **janice234ford@gmail.com**

Colostomy UK's Private Facebook Group

With the pandemic hopefully soon behind us, it's been great to see support groups up and down the country resuming their face-to-face meetings and events. But what do you do if there isn't a support group in your area, or perhaps you can't make the meetings, or need the benefit of another's experience now? Well one solution is to join Colostomy UK's Private Facebook Support Group.



The group has been running now for 14 years. We made it 'Private' (or as it was called then, a 'Closed' group) in 2012. This was because we wanted to provide a safe environment in which ostomates, or soon to be ostomates, could support one another and share their experiences of life with a stoma. Added privacy also means that issues can be discussed openly with people who understand. As one of our early members said: "Let's face it, we don't necessarily want all our Facebook friends reading posts about poo!"

The group is now very popular indeed. When we went 'private' it had around 250 members. Six years later in 2018, it had 6,000, and it didn't stop there: earlier this year we reached the 11,000 mark! Of course, not every member is active all the time. Many members just read posts. Others will ask for help as and when they need it, such as seeking some practical advice for a stoma-related issue. Others post more frequently.

There's also a good amount of 'stoma' humour, which can be uplifting in its own right. Joining is easy: simply search online for 'Colostomy UK Support Group' and click the join button (see p. 33).

If you still aren't sure, then have a read of some of the recent feedback we have received:

> **"You are never made to feel stupid for asking questions but the help you are given is second to none."**

> **"I cannot thank enough Colostomy UK and group members since my emergency op three years ago... When you get home and time passes little things crop up, to know help and advice is here, I am ever grateful"**

Channel Islands

Guernsey

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

Jersey

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

England

Berkshire

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

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

Bristol

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

Buckinghamshire

High Wycombe Stoma Support Group
T: 0800 318965

Milton Keynes Stoma Support Group (MKSSG)
E: support@mkssg.org.uk

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

Cambridgeshire

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

Cheshire

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

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

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

Cleveland

Oops Group
E: stees.stoma@nhs.net
T: 01642 944324

Co. Durham

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

Darlington Support Group
Margaret Clothier
T: 0191 333 2184

Durham Stoma Support Group
Lynn Ridley
T: 0191 333 2184

Cornwall

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

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

Cumbria

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

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

Derbyshire

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

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

Devon

Devon IA
E: devon@iasupport.org

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

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

Dorset

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

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

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

Essex

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

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

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

Optimistic Ostomates
Stoma Care Team T: 01702 385158

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

Hampshire

Replummed Stoma Support Group
W: www.replummed.me

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

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

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

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

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

Herefordshire

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

Hertfordshire

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

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

Isle of Wight

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

Kent

Ashford Stoma Support Group
Malcolm Jones T: 07709 534463

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

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

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

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

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

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

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

Thanet Stoma Buddies Support Group
Kathy T: 01843 291 825

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

Lancashire

Bowel Buddies Preston
Calum T: 07463 880 652
Vine House T: 01772 793 344

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

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

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

Leicestershire

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

Lincolnshire

Grantham Support Group
Bobbie/Rachel T: 01476 464 822

London

Bowel & Other Cancer Support Newham
T: 020 8553 5366

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

Newham Stoma Support Group
Lauren King T: 020 7055 5576

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

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

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

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

Merseyside

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

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

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

Middlesex

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

Norfolk

James Paget Ostomy Support Group
T: 01502 585 955

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

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

Northamptonshire

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

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull T: 07714 479 320

Hexham Ostomy Group
Marie Douglas T:07941 433 600

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

Nottinghamshire

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

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

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

Shropshire

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

Somerset

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

Staffordshire

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

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

Suffolk

East Suffolk Ostomy Group
Ian Denison T: 01473 684865

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

Surrey

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

Guildford Stoma Support Group
T: 01483 571122 ext 2558

Sussex

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

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

East Sussex Stoma Support Group
Vicki Blaker T: 0300 131 4603
E: esh-tr.StomaCareDept@nhs.net

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

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

Tyne and Wear

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

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

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

Warwickshire

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

West Midlands

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

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

Wiltshire

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

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

Worcestershire

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

Yorkshire

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

Airedale Stoma Support
Sue Hall T: 01535 646 373

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

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

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

Bradford Stoma Support Group
Lisa Hall T: 07552 276 747

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

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

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

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

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

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

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

Isle of Man

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

Northern Ireland

County Antrim

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

County Armagh

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

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

County Down

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

Ulster Hospital
Hazel/Martina T: 028 9055 0498

Londonderry

Causeway Support Group
Mary Kane T: 028 7034 6264

Republic of Ireland

County Mayo

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

Dublin

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

Scotland

Ayrshire

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

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

Greater Glasgow

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

Moray

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

Scottish Borders

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

South Lanarkshire

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

West Lothian

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

Wales

Aberystwyth

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

Conwy

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

Gwent

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

Mid Glamorgan

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

Pembrokeshire

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

Powys

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

Rhondda Cynon Taf

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

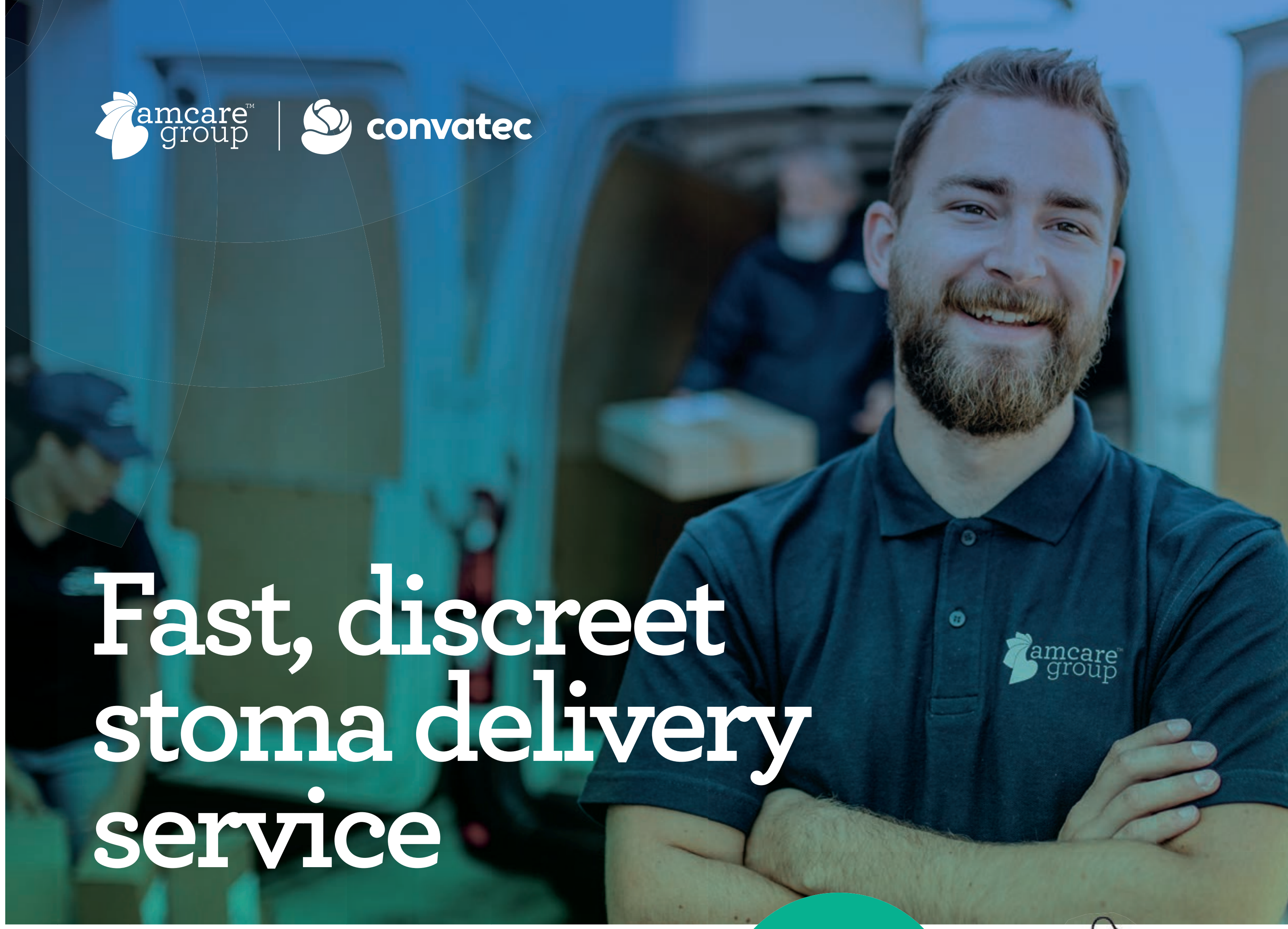
Swansea

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

Make your donations worth 25% MORE at no extra cost to you!

If you're a UK tax payer, tick the Gift Aid box on the donation form so that we can claim an extra 25% from HRMC at no extra cost to you. Gift aiding your donation provides us with more funds to focus on the things which matter to you, such as providing support through our stoma helpline, campaigning for stoma-friendly toilets, producing this magazine and getting more ostomates up and active!
For more information, email: **fundraising@colostomyuk.org**

[redacted]




Emperor
MAX 70mm
Emperor
MAX 70mm