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Colostomy UK's Award-Winning Magazine

Tidings

Supporting & empowering ostomates

Young Heroes Special

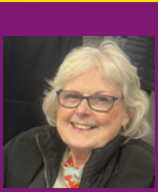
We celebrate young ostomates making a positive difference to the wider stoma community

Tidings joins the digital revolution!

Discover why and how we're taking your favourite magazine online. Page 33

PAGE 10

Managing Mucus



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Caring for your stoma outside of working hours

**Real stories
Real people**

Colostomy UK

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We help people get back to the business of living after stoma surgery.

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- Donate online at **ColostomyUK.org/donate** or by scanning this **QR code**

Thank you!

From
Colostomy UK

Colostomy UK

Editorial Team

Editor, Writer & Researcher
Ross Othen-Reeves

CEO
Libby Herbert

Colostomate & Volunteer
Jackie Dudley

Ostomate & Volunteer
Jillian Matthew
Holly Broomfield

Former Ostomate & Volunteer
Leslie Mello

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It is available online for free at: www.colostomyuk.org/support/tidings

If you would like to change your Tidings subscription from a physical copy of the magazine to the online version, please contact us on 0118 939 1537, or use your smart phone to scan this QR Code.

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Dear readers

Welcome to the first Tidings issue of 2025! Is it just me, or does it seem like we were celebrating the arrival of the new Millennium only five minutes ago? Sometimes it truly feels like we're living in the future.

Colostomy UK is doing all it can to move with the times, which is why many of our readers will have received this Spring edition of the magazine in digital format, sent via email, rather than receiving a physical copy through the post.

Hopefully this is not a complete surprise for those of you now receiving the online version, as you should have received several emails on the topic before now. Nonetheless, we understand that change can be difficult for some, which is why we've a dedicated article explaining the reasons for this transition on page 33.

We're also marking the first 25 years of the century by dedicating this edition of Tidings to young ostomates, all born since 2000.

This includes the inspiring story of 20-year-old, Teigan Griffiths, whose endless optimism saw her through her most challenging times and helped keep her dreams of becoming a police officer alive (p.14). We also hear from Jessica (10) who explains how she met her now close friend, Jax (11), through their efforts to raise stoma awareness. Their achievements led to the pair receiving Youth Awards in Westminster (p.9).

Hunter Garrod (9) and Jack Dale (9) are two more young achievers who have gone above and beyond in their awareness-raising and fundraising efforts for stoma-related causes. The two sports-mad boys share all their thoughts on living with a stoma in our Q&A (p. 39).

Keeping with sports, football-loving Jake Cassidy (14) explains how, despite many setbacks, having an ACE stoma and an ileostomy haven't stopped him from playing 'the beautiful game' (p.30).

Over the past couple of months, the Editorial Team has also been supported behind the scenes by aspiring young writer, Oliver Holmes (14), who has been volunteering with us. Oliver both interviewed and wrote Jake's story, and we're sure you'll agree he's done a fantastic job of it. It probably helped that Oliver is as football-obsessed as Jake is! (p.30).

Beyond our young persons' special, we have a Real Lives feature focused on mother-of-three, Nita, whose permanent stoma helped alleviate persistent faecal incontinence caused by an injury during childbirth (p.23).

As well as answering all your exercise-related questions, our regular fitness columnist, Jo Prance, also opens up about a recent accident which risked damaging her rectal stump, formed following stoma surgery. Jo describes her gentle journey back to her active life (p.18).

We have all your favourite regular features too, including Fundraising and Campaigning updates, and our Dear Nurse column discusses how to find the perfect stoma products (p. 42). There is also practical advice on how to manage rectal mucus (p. 10), and what to do if you're in need of stoma-care support outside of standard working hours (p. 13).

Finally, Bob Bailey reminisces over one of Colostomy UK's long-standing sister projects which recently came to an end. The Romanian Ostomy Patients Support Foundation was founded just before the turn of the Millennium and supported Romanian ostomates and stoma nurses (p.26). As this much valued initiative comes to a close after almost 30 years, I'm sure Bob is one person who would agree that time does indeed fly.

Ross Othen-Reeves
Editor, Writer
and Researcher

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Ostomy Care
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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.
Registered charity no. 1113471

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!

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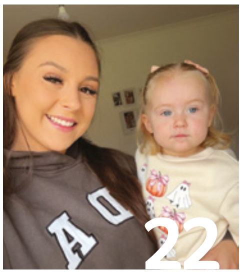
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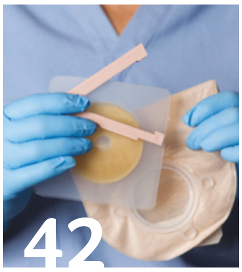
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Donating to Colostomy UK

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

campaigns

Giovanni Cinque
Marketing & Campaigns Manager
GetInvolved@ColostomyUK.org

Colostomy UK has been working with the Department of Health and Social Care (DHSC) on a project that examines how stoma products are assessed and prescribed. Our Marketing and Campaigns Manager, Giovanni Cinque, gives an update on progress so far.

Drug Tariff Part IX Consultation

In 2023, The Department of Health and Social Care (DHSC) issued a consultation focusing on Part IX of the 'Drug Tariff' – the list of medical devices which are approved by NHS Prescription Services to be prescribed by healthcare practitioners, such as GPs and stoma nurses. Despite the title referring to 'drugs', stoma bags and associated equipment are included within this list.

Unlike many other areas of healthcare, there has been little change to Part IX of the Drug Tariff since it was established nearly 50 years ago. During this time, the world of stoma products has evolved dramatically, and there have also been significant changes in the manufacturing and delivery markets too.

The current list within Part IX is not very user-friendly and is set up in a way that makes it difficult to compare products. This can have an impact on patient choice, as currently there is a heavy reliance on advice from stoma nurses and other clinicians, whose knowledge may be limited to the brands they are familiar with. Making it easier to compare products could therefore widen the range of options that clinicians feel confident to recommend. This would then hopefully lead to better care.

> **With NHS spend on stoma care steadily increasing to over £300 million a year in England alone, the DHSC believes it is more important than ever that Part IX is modernised to ensure people receive the right product, at the right price, and in the right place.**

Colostomy UK was one of several third-sector organisations that were invited to feed back on the proposals to the DHSC. Our role has been to ensure that the DHSC fully understands the experience of people living with a stoma, including ostomates' experiences of stoma care provision and the quality of products.

We were asked to respond to several different points, which included:

Ensuring Part IX consistently includes products that are of good quality and effectiveness.

Ensuring that Part IX's product list is refreshed going forward, and existing and new products are only adopted or continue to feature on the product list if they are able to demonstrate value in terms of cost effectiveness to the NHS and to patients.

Ensuring the new Part IX process encourages innovation that will lead to improved quality of life for patients.

Following the consultation period, the DHSC has decided to proceed with the following updates to Part IX of the Drug Tariff:

More stoma-care products will be compared under Part IX of the Drug Tariff.

- These comparisons will be based on both clinical reviews as well as patient input. The hope being that this will lead to better quality care.

Introduce a renewal process for Part IX

- A renewal process will mean that stoma-care products on the list will always be up-to-date, and ensure the NHS gets value for money.
- The renewal process will happen every 4 or 5 years, and any products which don't meet current standards will be removed from the list.

The creation of a new Advisory Panel to oversee the assessment of stoma-care products

- The new Advisory Panel would be made up of clinical professionals and people living with a stoma.
- Their job will be to assess both new products before they are added to the Drug Tarriff list, as well as reviewing stoma-care products which are up for renewal.

We are aware that there is some disquiet amongst stoma care companies, which are worried that these changes will have a negative impact on patient choice and product innovation. However, we are broadly supportive of the process because we believe that, while there may be some short-term challenges, far greater transparency is required around pricing and evidence of product innovation than currently exists.

Our work on Part IX is part of our asks of the UK government that we published in 2024.

We will continue to work closely with the DHSC to make sure people living with stomas have access to the right product for them, at the right time, and at the right price for the NHS, as well as receiving better access to support from healthcare professionals when needed.

Support future generations living with stomas – leave a legacy gift in your will

Your legacy will help Colostomy UK secure a positive future for people living with stomas, ensuring we can adapt and respond to their needs. It truly is the gift of a lifetime!

Whatever your interest or passion, a legacy of any size can make a difference. You can direct how you wish your gift to be spent, or leave it to us to apply it where it is most needed.

For example, your legacy could be put to excellent use:

- ensuring our support services are available to everyone who might need us, however and whenever they choose
- expanding our range of Active Ostomates classes, both online and in person, to help more people build confidence, fitness and strength after stoma surgery
- updating our information library, ensuring that all the topics that are of help to ostomates are covered, and they are available when and how they are needed

We've teamed up with FreeWills.co.uk, an award-winning online service, to offer you the opportunity to make your own fully comprehensive and legally-binding Will completely free of charge. The three simple steps take about 15 minutes to work through, with live support from their Will specialists, and you have the added reassurance that your Will will be checked, vetted and approved by a solicitor. They can also update and amend existing Wills.

Leaving a gift in your Will is a simple and tax efficient way to support people living with stomas - it won't cost you a penny during your lifetime, and is free from inheritance tax!

To leave us a legacy:

- State in your Will that you would like to leave a gift for Colostomy UK.
- Include our full details to make sure that your gift goes to the right place: Colostomy UK, registered charity number 1113471, company number 05612173.

If you'd like to talk to us about a legacy gift, please contact us on 0118 918 0501 or email hello@colostomyuk.org

You can find more information on our website: www.colostomyuk.org/get-involved/fundraising

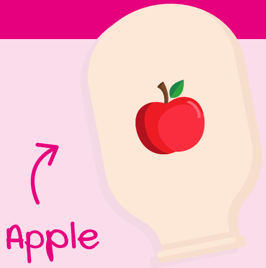
Colostomy UK advises anyone making or updating a Will to seek independent advice from a recognised law firm and properly qualified solicitor – Wills are legal documents and, if they are not worded properly, they may not have the effect that you wish. And if you die without a Will, the law decides who gets what!

Friends for Life:

How Jessica and Jax Inspire Community, Charity, and Change Together

BY LESLIE MELLO

Tidings' regular contributor, Leslie Mello, kick-starts our Young Persons special edition with the heartwarming story of two very good friends, Jessica and Jax.



Jessica, now aged 10, has lived with her stoma — lovingly named "Apple" — for much of her life. Instead of holding her back, this experience has inspired her to raise awareness about living with a stoma and bring people together so they can share their stories and support one another.

2022 was an exciting year for Jessica. In early August that year, she met Jax (aged 11) for the first time when his family visited Liverpool. Jax is also living with a stoma and the pair realised through social media that they were both working hard to raise awareness around the topic. Later that month, Jessica and her family travelled to Jax's hometown. Their friendship blossomed through their shared experiences as young ostomates and their involvement with 'A Bear Named Buttony,' a charity that helps children and young people adjust to life with a stoma, by gifting a bear with its own stoma and other helpful items. Both Jessica and Jax are now ambassadors for this charity, and Buttony Bear is something they love supporting together.

In September 2022, Jessica helped organise a charity day dedicated to children with stomas, their families, and friends. The following month, October 2022, brought a remarkable honour: both Jessica and Jax received the British Citizen Youth Award in Westminster, recognising their incredible work.

October 2022 was also when Jessica and her mum, Kim, first asked Liverpool to light up local landmarks in purple for Stoma Aware Day. That year, the Radio City Tower and the Mersey Gateway Bridge shone brightly. The following year, they encouraged more buildings, including Bootle Town Hall, to join in.

> On that second occasion, Jessica and a few of her young ostomate friends spontaneously collected donations in the street, using just a jumper to gather coins, showing that even small efforts can have a big impact as they raised almost **£100!**

(Kim has since learned that a street collection permit is required to raise funds this way, so please contact your local council before attempting this yourselves!)

In August 2023, Jessica and her mum hosted another charity night, this time welcoming both adults and children with stomas, as well as their families. It was exciting for everyone to see how the friendly community they'd built continues to grow. Then, in October 2024, John George — who once had a stoma — saw Jessica's posts online and offered to perform his Elvis impersonator act free of charge. Although John's since had his stoma reversed, he's still deeply committed to helping others who are on their stoma journey. His heartfelt performance made the night even more fun and meaningful.

Jessica's journey, from lighting up landmarks to finding a friend in Jax, and earning national recognition, shows that anyone — no matter their age — can make a genuine difference. She and Jax have built a legacy that inspires greater understanding, acceptance, and hope for all those living with a stoma.

Managing rectal mucus

BY HOLLY BROOMFIELD

Tidings contributor, Holly Broomfield, shares tips on how to manage rectal mucus, which she's gathered through years of volunteering for Colostomy UK, as well as her own lived experience.

As one of Colostomy UK's helpline volunteers, I've noticed that mucus can come as a surprise to many new ostomates. Callers often say they were not warned by their healthcare team, or that they experienced information overload, whilst coming to terms with their stoma in hospital. So what happens when you pass rectal mucus, and what can be done about it?

Mucus is normal for ostomates who still have their rectum, which continues to produce mucus even after stoma formation. Mucus can be clear or putty coloured. If you have a loop stoma, it can also be brown, as a small amount of poo can pass into the rectum. The consistency is solid, sticky, runny or even liquid.

Both colour and consistency can vary each time, as can the volume produced. On the helpline I describe it as similar to a snotty nose – sometimes it is non-existent, and at other times streaming! If you have a cold, the amount of rectal mucus may increase. Hormonal fluctuations can also impact mucus experienced by women. Occasionally, ostomates may not notice mucus until several months, or even years, after surgery.

How an ostomate manages mucus, often depends on its consistency. When solid, the sensation may be similar to the feeling you had when you needed the toilet, pre-stoma. If so, you can sit on the toilet and bear down (as though emptying your bowels). If you do not have much sensation, you can hold a wad of toilet paper against your anus, which can assist with pushing.

> **If the mucus is liquid, it can catch an ostomate by surprise. Ostomates of both sexes can wear a sanitary pad in their underwear to help manage this. It is important to keep the area clean and dry and a barrier cream may help prevent discomfort.**

Some ostomates who struggle to push, use glycerine suppositories, which can be purchased from a chemist (do check with your healthcare professional before use). Suppositories are bullet shaped and made of a jelly like substance, which is inserted in the rectum for around 10 minutes, usually whilst laying down. These irritate the lining and so help the mucus to pass. Depending on mucus' consistency, pelvic floor exercises can also help with control.

Personally, I use a mini rectal irrigation system on a weekly basis. It's very quick and gives me peace of mind. Essentially, it is hand held, rubber device, shaped like a bulb, that you fill with water. A nozzle fits on the top, which is then inserted into the anus whilst sat on the toilet. As you gently squeeze the bulb, the water empties into the rectum, washing the

mucus straight into the toilet. An extendable tube can be added to separate the bulb and nozzle, for those with dexterity needs. Some examples of systems include the Qufora IrriSedo Mini, Mini Go and Flex or the Aquaflush Mini Compact. These are available on prescription, however approval must first be sought from your stoma nurse or consultant.

> **Importantly, any mucus which contains blood should be reported to your healthcare professional, as this could be a sign of inflammation or infection.**


Supporting and empowering ostomates
Colostomy UK
Rectal discharge
following stoma surgery
www.ColostomyUK.org
Stoma helpline:
0800 328 4257
24/7

Further information can be found in Colostomy UK's booklet 'Rectal discharge following stoma surgery,' downloadable from our website, or ordered in hard copy via, our stoma helpline (0800 328 4257).

Caring for a Stoma Workshops

BY SHAUNA HEMPHILL

Colostomy UK's Shauna Hemphill shines a spotlight on one of our most impactful training workshops.

Colostomy UK works with organisations, venues and employers across the country, providing stoma care training and ensuring their facilities are stoma-friendly and accessible.

This includes our 'caring for a person with a stoma' workshop aimed at people who provide, or may have to provide, stoma care. The workshop covers the essential knowledge and skills needed to successfully deliver stoma care and is facilitated by a qualified stoma care nurse.

We have been running the workshop since 2015, mainly online, to different organisations and individuals such as NHS departments and care homes. Feedback has been overwhelmingly positive - respondents rated themselves as either 'very confident' or 'confident' to deliver basic stoma care after completing the workshop. On average, the delivery of the workshop has been rated 5/5 by attendees who provided feedback.

We also provide bespoke stoma aware training for organisations who want to tackle attitudes, understanding, and behaviours towards people living with a stoma. The training is tailored to the type of service each organisation offers, as well as their current facilities, such as toilets. We act as a 'critical friend' to educate each organisation and their staff and guide them on how to make their venues stoma friendly. To enrich the learning experience, our sessions often feature one of our volunteers with lived experience of a stoma.

If you would like your organisation to get involved with stoma care workshops or stoma awareness training, we'd love to hear from you:getinvolved@colostomyuk.org

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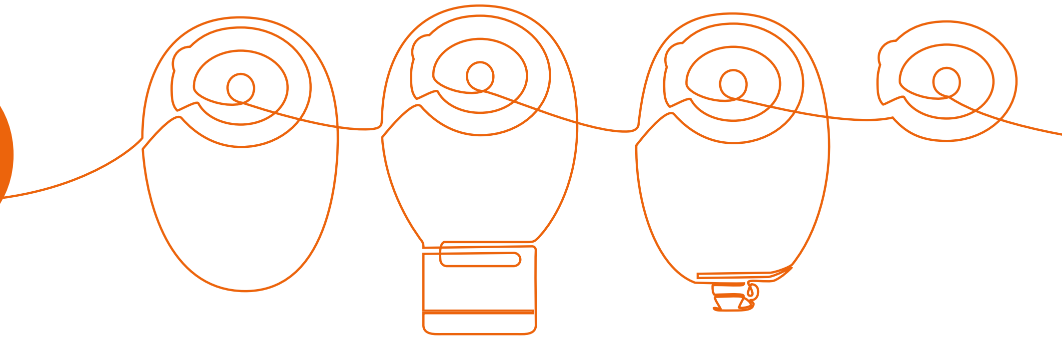

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Be prepared:

Caring for your stoma outside of standard working hours

BY SUE HATTON AND JACKIE DUDLEY

Colostomy UK volunteers, Sue Hatton and Jackie Dudley, offer ideas for what to do in the event of needing stoma care support or products outside of working hours – as well as tips for avoiding the problem altogether.

Having a stoma formed can be a bewildering and disconcerting time, regardless of whether the surgery was planned or an emergency. Emotions are running high, medication may be fogging the mind, and then on top of it all, there is so much to learn and remember about caring for your new stoma.

You may also find you're a little low after all the attention before and immediately after surgery. It's once you're alone and learning to cope that talking to someone who has walked a mile in your shoes can help.

There is medical support available, but that support is often only provided within standard working hours of 9 – 5, despite your stoma working (and sometimes misbehaving) 24 hours a day.

Then you find the weekend is ahead of you and you have concerns:

- You might be losing confidence in how to manage your stoma without the support of your stoma care nurse.
- You have a problem! (leaks, sore skin, pancaking...)
- You think you don't have enough stoma bags to see you through the weekend.
- You don't know who to ask for help and advice.

What to do:

Before leaving hospital

- Insist on more than just a few bags before leaving. This is not demanding, this is your right, and such forward planning avoids the risk of running low on bags during these early days, when you and your stoma are still getting to understand one and other.
- Request the name and contact details of your stoma care team. This is standard practice and should be provided without issue from your medical team.
- Some Hospital Trusts also provide new ostomates with a dedicated contact point at the hospital. But this varies from Trust to Trust (some don't offer this service at all). Always enquire into this option regardless.

Join a Support Group

- Support Groups can be invaluable for creating new friendships with ostomates in your local area - and who best to turn to when in need of advice than a friend?
- Support Groups can be found all across the country and are listed at the back of Tidings (see page 47).
- You can also contact our Community Engagement Lead, Shauna, for more advice on this: shauna.hemphill@colostomyuk.org

Contact Colostomy UK

- Colostomy UK has over 100 trained volunteers, all of whom have experience of living with a stoma. They are available to talk to 24/7 and are contactable via our Helpline on

0800 328 4257 ☎

- The volunteer will listen and advise you of the steps to take to solve your problem. They will reassure you, and help you regain your confidence. They may – through experience – have the answer to your problem immediately.
- We are unable to answer medical questions, so if the problem requires a medical answer, we will be able to signpost you to the relevant organisation or professional who will be able to support.

Other options

- Do you have a friendly pharmacist who may have stoma bags available to purchase?
- Do you have a contact number for your stoma bag supplier, and do they offer a support service?
- Does your GP have an "out of hours" contact number?

Anything is possible if you believe in yourself

BY TEIGAN GRIFFITHS | EDITED BY JILLIAN MATTHEW

20-year-old Teigan Griffiths shares her story with us, reminding us all of the power of positive thinking

I started to notice a change in my bowel habits around the age of 15-16, which I put down to mild constipation that occurred now and again. But then I started noticing I wasn't emptying my bowel for around 2-3 weeks a time.

After frequent doctor appointments and hospital visits, I was prescribed laxatives for constipation. However, my symptoms worsened, I started getting extreme pain in my stomach after eating and drinking. By the age of 16, I was on ten laxative sachets a day. Despite this, I would still only go to the toilet once every 3-4 weeks. My pain escalated and my weight dropped rapidly. I'd spend weeks in hospital receiving treatment and undergoing investigations. By the age of 17, I was in so much pain and discomfort, I was unable to leave the house. My days consisted of pain, laxatives and four enemas a day, but still nothing seemed to work. I was prescribed morphine, which made me extremely drowsy, and I spent most of the day on the toilet. Further tests showed that the nerves and muscles in my bowel had completely shut down and stopped working. I was told that a possible way to treat my symptoms was an ileostomy. My illness was so complex that it couldn't be done in my local hospital, then I was told I was out of the catchment area. By this time, I only weighed five stone, and I was so weak that I could barely walk. I relied on my parents to do everything for me – utterly heartbreaking for my family to witness. I remember the words of my parents: "This can't go on much longer, our daughter's life is slipping away from us".

I went to private healthcare where my needs were seen as urgent. I was told I needed stoma surgery as soon as possible. However, given that I was so underweight, operating was highly risky. I was put on Total Parenteral Nutrition (nutrition received intravenously), to try and build up my weight. However, I caught sepsis and had abscesses on my lungs. I was extremely poorly and risked having to go to ICU.

Luckily, it didn't come to this, although I still hadn't gained weight. Surgery still went ahead in March 2023. My bowel had almost doubled in size and there was no option but to remove it and have a permanent stoma formed. Unfortunately, when I was discharged home, I began to deteriorate. I was vomiting and not keeping anything down. I remember my dad's words: "I came home from work that day and I thought again we were going to lose you, I knew something really wasn't right". I was rushed back to hospital where a CT scan showed that I had a hole along with bleeding and fluid in my abdomen. I had drains for the fluid and the bleeding. Recovery went well after that.

I am now living my life with 'Roma the Stoma' (my mum suggested the name because of the roaming journey I've been on). At first, I really didn't think I would adjust to the new lifestyle, I was so worried about my confidence and not being able to do all the things I wanted. However, my stoma completely saved my life and changed it for the better. I couldn't be happier. I still have some way to go. I am still underweight, but I'm working on it and each day I'm becoming stronger. Last year, despite all I went through with my health, I achieved an A* in Criminology, and A grades in Sociology, Psychology and a Welsh Baccalaureate in my A levels.

I am working as a Customer Experience Advisor, but my hopes are to get an apprenticeship with South Wales Police, to achieve my dream of becoming a Police Officer. I contacted South Wales Police to tell them about my situation and they said it wasn't a problem. They would even provide a specialist reinforced uniform for me to protect my stoma bag. I am currently training to become a Volunteer Special Police Constable. Apprenticeships don't come up very often, so I thought in the meantime I would volunteer and get experience to see if it's for me. Training is two evenings a week and weekends – the same training as a police constable would do. I will finish in April and then join police officers and do day to day police work.

It's a lot to fit in around work but after what I've been through, I thought: "you just have to grab life with two hands". I have wanted to join the police after being bullied from a young age and spending a lot of time with police officers while I was going through that difficult time. I decided I wanted to help others in a similar situation. I like a challenge, and I think the varied work of being a police officer will suit me.

I believe I will get there, no matter how long it takes or how difficult the journey will be. I have the best support system around me – my amazing family who have been there every step of the way, along with some truly incredible people who have supported me. They have always been behind me through the most difficult times. "Anything is possible if you believe in yourself."

My message to anyone undergoing stoma surgery is: "No matter how difficult life may be right now, and no matter how trapped you feel, or how scared the thought of having a stoma may be, once you adjust, it really isn't that scary." It turned my life around and has allowed me to live my life in ways I never even imagined.

When I look back at everything I've been through, it gets me emotional. I couldn't have got through it all without the unconditional love and support of my parents who haven't left my side throughout my whole journey. I now live each day to the fullest and never take anything for granted as I know it could all be taken away in a blink of any eye.

Everyone is unique and different, shine in your own way.

fundraising

Megan Lowden
Fundrasing Executive

Our Fundraising Executive, Megan Lowden, gives us the lowdown of the many ways our supporters have helped raise vital funds for Colostomy UK over the past three months.

1 Million Steps for Stoma

Ciara McGrillen and her sisters took on the incredible task of walking 1,000,000 steps between them during the month of October to mark Stoma Aware Day. They were inspired by Ciara's 3-year-old son, Cody, who underwent stoma surgery at just two days old. Between them they raised an incredible £1,175 in vital funds for our charity.

James' Run for a Cause

James Marshall is taking on the Victoria Half Marathon in April to raise funds for what he calls 'an incredible cause that's close to my heart'. He told us that *"Running a half marathon won't be easy, but I'm inspired by the courage and resilience of those living with a stoma every day. Knowing I can make a difference for them will keep me going, even when the miles get tough"*. He is well on his way to smashing his fundraising target already!

Roy's Birthday Gift

You may remember Robert (Roy) Ferguson from the 2024 Spring edition of Tidings magazine, when he shared his real life story of navigating the world with his stoma using music and positivity. This year Roy decided to raise funds for us once again while celebrating his 70th birthday in December. Together with his nearest and dearest, Roy donated £906 in vital funds to help continue the work of Colostomy UK.

Country Style Foods Update

In the last edition of Tidings, we covered Country Style Foods in Stockton, who raised over £1,500 during the summer. Thanks in part to our wonderful young fundraiser Jack's mum Zoe, the final total donated to us was £5,060! As their Charity of the Year in 2024, we recently attended an event where we were presented with the cheque. We are, once again, their Charity of the Year in 2025 and we can't wait to see what this year brings!

If your company works has designated charities that they support each year, why not ask if they will support Colostomy UK? We would love to have a chat with you!

Tesco Extra Raises £500

Huge thanks to Kirk, Lyndsey, Robert and all at Tesco Extra in Newtownbreda, Northern Ireland, for nominating us as their chosen charity, and recently rewarding us with a brilliant £500 from their Tesco Bookcase for Charity initiative.

Running Through the Storm

Rebecca Birtwell battled Storm Bert with her friends and family, running the Silverstone Half Marathon for us on the 24th of November! Rebecca has lived with Ulcerative Colitis since she was three years old, and had her ileostomy formed at age nine. 34 years on she braved the elements and raised an incredible £680 in vital funds for us! Look out for Rebecca's courageous story in a future edition of Tidings very soon!

Finally, thanks to those at Holman Bowls Club in Cornwall for their donation of £202, raised from their Christmas raffle!

Community Clubs

If you are part of a community club, why not encourage them to raise funds for Colostomy UK? Reach out to us using the details above to find out more on how you could support us, we would love to have a chat with you!

Christmas Appeal

Lot of people also granted Colostomy UK's Christmas wish by supporting our Christmas fundraising appeal. Together you all raised over £8,000 during the month of December and we could not be more thankful!!

Unity Lottery

Did you know that we are partnered with Unity Lottery? Not a week has gone by where someone has not won, with someone recently winning £1,000!! For more info, search for Colostomy UK - Unity Lottery

Step Up for Stomas, Active April!

Could you support Colostomy UK this year, enabling us to continue to be there for you and the over 200,000 people living with a stoma in the UK?

Step Up for Stomas is back, and this year we are asking you to Get Active in April! Whether you walk 200,000 steps during the month, do 200 squats a day or create your own active challenge that best suits you – get involved and raise vital funds for Colostomy UK.

For more information please see pages 36, or visit **www.colostomyuk.org/getinvolved/activeapril**

We'd Love to Hear from You

If you want to chat over any fundraising ideas with us, please email us at: getinvolved@colostomyuk.org or give us a call on 0118 939 1537.

Fundraising is invaluable for Colostomy UK, helping us to cover the running costs of all our support services, including Tidings.

Bumps in the Road:

Fitness Guru, Jo Prance, opens up about her recent personal challenges

Most readers will be familiar with our regular 'Ask Jo' column, in which Jo Prance answers all your fitness-related questions. Yet few will be aware of the struggles Jo herself has had to overcome in recent months.

Despite having a high level of fitness, I'm not immune to life's challenges. Many of you have likely faced significant difficulties and understand, firsthand, the profound effects they can have on your physical and mental well-being. I wanted to share my approach to overcoming these setbacks.

In August 2024, I slipped on a tiled floor at home and landed heavily on my lower back, impacting my sacrum. The pain was intense and radiated into my rectum. My immediate concern was whether I had damaged my rectal stump, which was formed following surgery for a Hartmann's colostomy five years ago.

Over the next four weeks, recovery was slow. Walking was a struggle and sleeping impossible. I was still teaching, but moving was challenging. My pelvic floor and leg muscles repeatedly spasmed and clearing rectal mucus was difficult and painful.

The initial CT scan in A&E after my fall failed to detect I had fractured the sacrum. It wasn't until four weeks later — on the very day we left for our holiday — that the results of a private MRI scan revealed the true cause of my persistent pain.

I was advised to avoid twisting my pelvis, and to stop all impact exercises for 3 – 4 months, as well as any exercises involving sitting or lying.

We had planned an active water sports holiday, which was set to be another milestone for me as an ostomate. While I managed to make the trip with the aid of a coccyx cushion, I had to come to terms with taking on a more sedentary role as a spectator.

This unexpected downtime gave me a chance to reflect on the many times I've overcome setbacks and recovered from surgeries — what I call "bumps in the road." Life's journey is unpredictable, but these moments remind me of the strength it takes to keep moving forward.

It gradually sank in that the months of dedicated training I had put in for upcoming swimming competitions were now undone, along with the significant strides I'd made carrying a weighted rucksack in preparation for a charity hike up Mount Kilimanjaro, scheduled for October 2025.

Initially, I felt frustrated and, unsurprisingly, had moments of self-pity. However, I quickly recognised the need to shift my mindset, choosing to focus on what I could do, rather than dwelling on what I couldn't.

I adapted my training to work around these limitations. While I could swim using only my arms, I avoided kicking and tumble turns. At first, I couldn't lift weights or use any gym cardio machines, but after six weeks, I began easing back with very light upper-body weights in a standing position. I embraced these adjustments and found motivation in the steady progress I was making.

Setbacks are an inevitable part of the recovery journey that many of us will face, but what truly matters is how we choose to move forward. For me, focusing on what I can do, practicing patience, and drawing strength from my resilience to adapt and overcome each challenge, is what has got me through these difficult times.

Ask Jo

BY JO PRANCE

Now over to Jo's regular column, where she answers all your questions on how to stay in shape while caring for your stoma

I have an ileostomy which I've had for years now, I was wondering if it will be okay for me to use an ab roller wheel for stomach exercises, that you push forward and back to exercise my tummy muscles?

An ab roller strengthens core muscles by engaging multiple muscle groups, primarily the abdominals, but also the lower back, hip flexors, and shoulders. However, it requires significant core strength to control the movement of rolling the wheel forwards and backwards which may be too much for a stoma. Incorrect form can put excessive strain on the lower back, particularly if the core muscles are weak, making this exercise one that demands extra caution.

If you are someone who was very active/athletic before surgery - how should you go about getting active again? Should you start slowly and gradually progress, or is it ok to go straight back to what you were doing before?

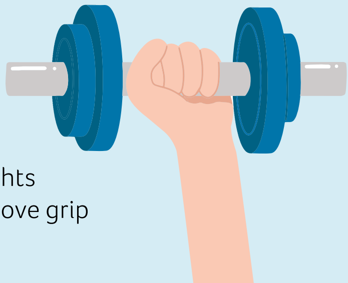
Even if you were athletic before surgery, it's important to ease back into exercise. Recovery time and the ability to return to exercise or sports depends on the type of surgery you had, any complications during recovery, and the demands of the activity you're aiming to resume. The core powers all our movements, and the formation of a stoma can create a weakness in this area. Gradually, rebuild movement patterns by increasing exercise frequency, intensity, time, and type, as you adapt to stoma life and follow the guidance of healthcare professionals.

As we get older resistance training is proving to be important to maintain strength and mobility. What exercise can you safely do at the gym to ensure that you are engaging in muscle strengthening exercises, without putting you at risk of developing, or worsening a hernia?

Protecting your stoma by wearing support wear, or if recommended a stoma belt, is key. Start by lifting weights with good technique, exhale during exertion, avoid holding your breath, and gradually increase weight. Stop or modify the exercise if you feel pain or pressure around your stoma.

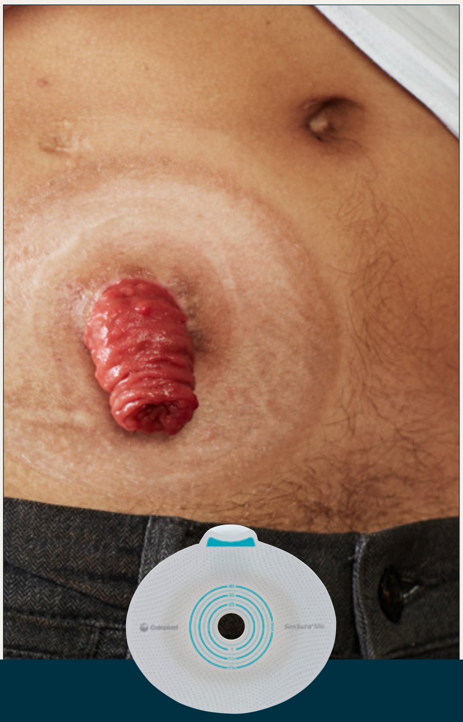
Here are a few suggestions:

- Resistance machines offer fixed, controlled movements targeting specific muscle groups. Most exercises are performed seated, providing additional support through features like backrests. Chest press, shoulder press, leg curl, and leg press are a few examples. They are a good option for controlling your range of motion and offering back support.
- Cable machines provide versatile, multi-directional push and pull movements. Performing exercises standing or seated without back support further challenges your core.
- Bodyweight exercises: wall sits, modified push-ups, squats, and lunges are effective exercises hat require no equipment. These functional movements also improve balance and coordination. They can be easily progressed by incorporating additional load, such as weights, for greater challenge.
- Free weights, like dumbbells, can be used in seated, standing, or lying positions, making them highly adaptable. Their smaller weight increments, 1kg upwards, allows for gradual progression. Holding weights helps to improve grip strength too.

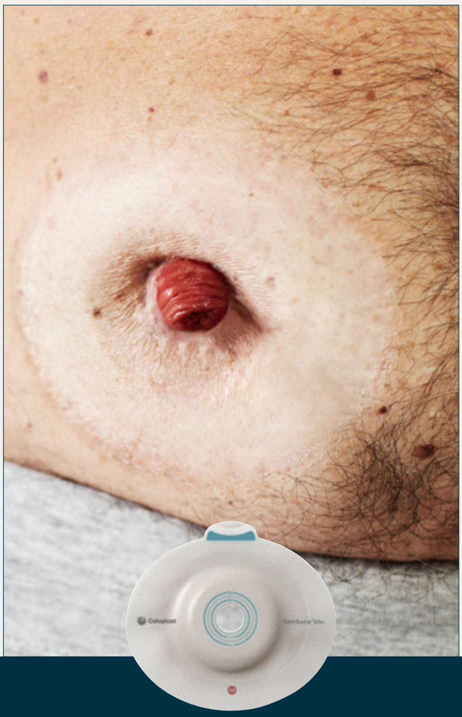


You can ask Jo any fitness-related question by emailing us at: Editor@ColostomyUK.org

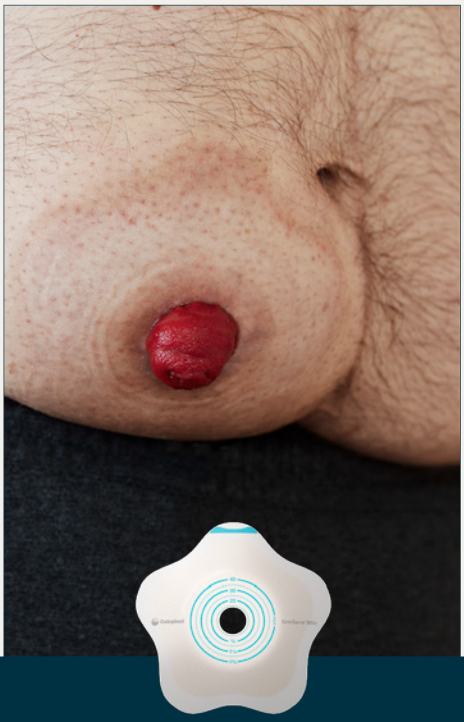
There's a Mio for every body



SenSura® Mio



SenSura® Mio *Convex*



SenSura® Mio *Concave*

Finding a stoma baseplate that is both secure and comfortable to wear can be challenging. Many ostomates worry about leakage, so it's important to find a stoma bag that provides a secure seal around the stoma and fits to your individual body shape.

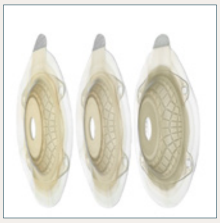
By choosing SenSura® Mio, you'll benefit from:

Flexible fit during movement

All SenSura Mio baseplates feature a unique adhesive technology called **BodyFit Technology** to provide secure **body** contact for protection and a flexible **fit** during movements.

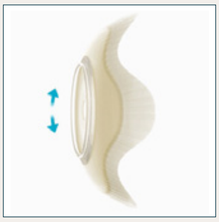
Support for a good night's sleep

The unique SenSura Mio full circle pre-filter is proven to significantly **reduce clogging** and **ballooning** compared to other leading brands[1]* to help you sleep through the night.



A better fit for your body

SenSura Mio Convex is available in three levels of convexity to provide a better fit for proven **leakage reduction**.[2]



A secure fit for bulges and curves

If the area around your stoma rises from your abdomen, you could benefit from **SenSura Mio Concave**, the only baseplate designed for bulges and curves.

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1. Laboratory report, Clogging resistance comparison of filter systems in SenSura Mio and competitor products, Coloplast data on file, 04.2023. Competitors: Dansac Novalife TRE, Pelican ModaVi, Salts ConfidenceBE, HollisterAF-300, Convatec Esteem +
2. Walker H, Hopkins G, Waller M, Storling Z. Raising the bar: New flexible convex stoma appliance - a randomised controlled trial. WCET. 2016;36(1): S6-S11.

* Based on lab data.

SenSura® Mio

Because your fit matters

"I feel like I'm an individual with choices"

Rosemary | Uses SenSura® Mio

"I can always count on SenSura Mio Convex because it fits me so well"

Deidre | Uses SenSura® Mio Convex

"It's so much easier to apply now. No more wrinkled baseplates"

Chris | Uses SenSura® Mio Concave

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☐ SenSura Mio ☐ SenSura Mio Convex ☐ SenSura Mio Concave

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Coloplast Ambassadors have been compensated for their time.

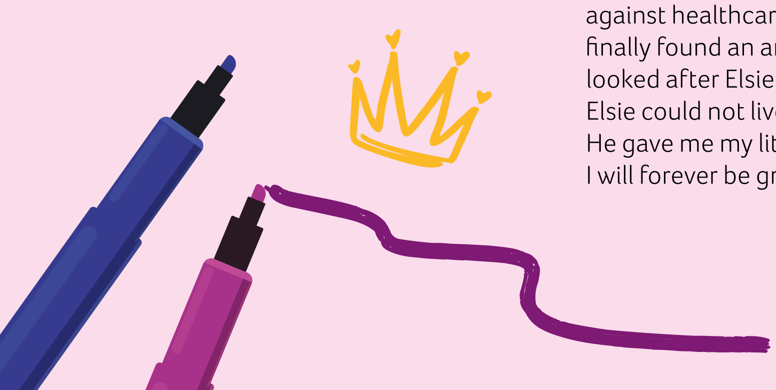
Coloplast

Ella & Elsie

BY ELLA RITCHIE

Ella and her daughter Elsie have raised well over £1000 for Colostomy UK and the children's stoma charity, A Bear Named Buttony, through activities such as quiz nights. Yet the journey from hospital wards to stoma superstars has been tumultuous. Here, Ella shares their story.

My beautiful brave little girl, Elsie (aged 2), was 17 months old when she had her colostomy surgery in June 2023. It was a very long journey before this. When I was pregnant with Elsie, a scan showed she had an echogenic bowel, which meant there was blood in her bowels. I was told this could mean a few things such as Down's syndrome, cystic fibrosis, severe infections... the list went on.



Elsie was born two weeks later with sepsis in her bowel. She was rushed to the Royal London Hospital where she spent two weeks in the Neonatal Intensive Care Unit (NICU).

Sadly, if Elsie's health had been investigated thoroughly prenatally, we could have avoided many situations since then, as the bowel infection could have been resolved by bringing labour on earlier.

Elsie has suffered with her bowel her whole young life. She couldn't pass bowel movements without suppositories, and she was on many different laxatives to try and help, but nothing did. She was in agony every single day, to the point that she would lose consciousness due to the pain she was suffering. After over a year of being Elsie's advocate, and fighting against healthcare professionals, we finally found an amazing surgeon who looked after Elsie so well. He agreed Elsie could not live the way she was. He gave me my little girl back and I will forever be grateful.

The surgeon initially attempted a couple of procedures that failed, leading him to suggest that a stoma would be her best option, due to the chronic constipation and evacuation disorder. I was so scared, but deep down I knew this was going to be the best thing for Elsie's life.

After her surgery was booked in, I was full of anxiety that I was making the wrong decision, but I had no need to be worried. Elsie spent five nights in hospital after her surgery and received the most amazing care. Her stoma has given her life back. She is in no pain and living her happy little life exactly how she deserves.

That's not to say the beginning wasn't very challenging for us both, with everything being so new. But Elsie was an absolute superstar. I used to be very nervous changing her bag but now it is just part of our everyday routine. I never needed to be scared!

Elsie is very proud of her bag and loves to show it off. Her stoma bags are white, and she loves to colour them in and make them unique.

The best thing about Elsie having her stoma is we can live every day without being worried she's going to be in extreme pain. She can still do everything anyone her age can. We still go swimming; we still go on holidays and adventures! There's no stopping us now! Whereas before we were very limited to what we could do due to the pain Elsie was in each day. It has saved us!

Q&A Sharon and Poppy

Sharon Jones shares her daughter Poppy's story

When and why did Poppy have her stoma formed?

Poppy has had chronic bowel issues since birth. After trying oral and rectal medication for five years it was decided to try an Ace Stoma when Poppy was six. After just five months of having her ACE stoma, her large colon began to fail completely and in March 2020 she had a subtotal (removal of her entire large colon) and ileostomy formed.

What's been the best thing about having a stoma?

Having a stoma has helped reduce the amount of pain Poppy was in and has meant we spend less time in hospital.

What's been the most challenging aspect of having a stoma?

Poppy really struggles with accepting her stoma and without the help and support from the wider stoma community I feel her struggles would be even more than what they are now.

Poppy also suffers with complete gut dysmotility and gastroparesis - a condition which causes stomach paralysis which leads to frequent nausea and vomiting. She also uses a wheelchair for her joint and muscle conditions. So she has a lot to contend with at her age.

What stoma-related fundraising and community-based activities have you and Poppy been involved in?

Poppy has been fundraising since she was five for a variety of charities. She is an Alder Hey Ambassador and some of the money she has raised has gone towards the Gastroenterology department to help other children with tummy problems. She has raised thousands for her local hospital that regularly treat her.

She has also taken part in Stoma Awareness Day for the past three years alongside fellow ostomates, lighting up Liverpool and surrounding areas and raising awareness in Liverpool town centre. Poppy has been recognised in Westminster Palace with a British Citizen Youth Award for her efforts in fundraising despite all her struggles. Poppy's previous primary school has also worn purple for the past few years on Stoma Awareness Day.

What incentivised you and Poppy to do the particular activities you've been involved in?

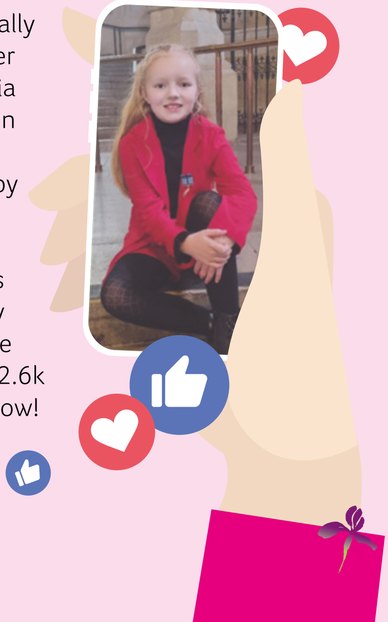
The stoma community is so supportive and understanding, so it's good to give back, and help raise awareness so that there is less stigma attached to having a stoma.

Do you have any ideas or plans for more stoma-related activities in the future?

Poppy will continue to support Stoma Awareness Day with fellow Ostomates for sure!

Anything else you'd like to add?

Poppy is really proud of her social media following on Facebook, called Poppy Power, where she documents her journey and life. She has nearly 2.6k followers now!



NAVIGATING THE UNEXPECTED:

Overcoming Medical Challenges After Childbirth

BY ROSS OTHEN-REEVES

Childbirth and early motherhood are usually an exhilarating milestone in life. Yet for some women this special time can prove especially challenging due to complications during labour. We hear from one such mother, who finally found peace of mind following elected surgery to have a permanent stoma formed.

No one knows how many women in the UK have a stoma formed due to complications resulting from childbirth. The data on the issue is surprisingly scant. One reason there is limited research in this area might be due to the fact that most deliveries in the UK are perfectly straightforward, as NHS data testifies.

That said, a number of complications can occur during delivery that may ultimately be alleviated through the formation of a temporary or permanent stoma. These conditions include anal sphincter and perineal injury and rectovaginal fistula (a connection between rectum and vagina for faecal material to pass through).

Nita* was one such mother who experienced an injury during the birth of her first child in 2001. She tore both her external and internal sphincter, resulting in faecal incontinence. But with a new baby to nurture, Nita ignored her symptoms and focused instead on her new motherly duties. In 2003, following the delivery of her second child, however, Nita's symptoms soon worsened.

At first, Nita's GP suggested the issue could be irritable bowel syndrome (IBS). This led the GP to initially prescribe anti-depressants. Unfortunately, these drugs had the opposite effect of what they were designed for, leading to Nita feeling suicidal at one point.

Nita understandably took herself off these pills, but continued to experiment with various IBS medications suggested by her GP. However, her symptoms continued to deteriorate. She found herself living on a restricted diet, yet her faecal incontinence became increasingly frequent. All while trying to manage two children and a career.

By now, she was certain that there was more to her condition than simply IBS and pushed for a referral to a colorectal surgeon. The GP finally agreed, yet months passed without her receiving any word of an appointment. In the meantime, Nita fell pregnant with her third child, which had not been anticipated, given her further problems with incontinence following her second delivery. As she explained,

> **"It was a surprise, because I had decided not to have any more kids, as I knew that the bowel incontinence was something to do with deliveries."**

So much time passed that Nita went to full term with her pregnancy and gave birth to her third child, all still without hearing back from hospital.

Her incontinence was now so impossible to manage that she "couldn't live", as she described it. Only at this point was it discovered that her referral had slipped off the hospital's IT system during a technical upgrade.

Finally, the hospital made contact and Nita was seen by a colorectal specialist. It appeared that she had developed passive incontinence due to an anal sphincter injury, with damage having worsened with each delivery. As Nita noted,

> **"If I had had C-sections with the second and the third deliveries, then it would probably have alleviated the symptoms."**

Six years on from the initial injury in 2001, Nita was fitted with a sacral nerve stimulator. This small, battery-operated device is implanted in the buttocks to aid control over the opening and closing of the bowel by stimulating the nerves to the anal canal. The procedure has to be repeated every five years to replace the battery. Nita, who also lives with fibromyalgia (a condition which causes widespread pain across the body), underwent two surgeries over the years to change the device batteries, yet she saw little change in her quality of life. As she explained:

> **"I would starve myself because I had no control at all. Due to the fibromyalgia pain, it wasn't like I could just run to the toilet either. So, it was a very difficult stage of my life - trying to manage both conditions at the same time as having three young children."**

When it was time for Nita to have the battery changed for the third time, she was understandably focused on finding a more effective solution to replace it with. Having researched stomas, she knew this was what she now wanted and pushed for surgery. Her medical team decided the best course of action was the creation of a loop colostomy, which is usually a temporary stoma - an operation which Nita underwent in December 2022. Unfortunately, as loop colostomies are not fully disconnected from the bowel, stool was still able to pass through to the rectum, which Nita still didn't have control over. As she put it,

> **"I was now doubly incontinent. I had the stoma bag and also had stool from the back passage".**

Given these ongoing challenges, Nita finally underwent surgery to form a permanent stoma in June 2024 and found instant relief:

"I have control and that's the main thing. At least I'm not incontinent anymore." she explained.

Whilst Nita's experience is exceptional, it does highlight some of the unique complications a small proportion of women face following childbirth. GPs are, by definition, generalised medical professionals. Complex cases such as Nita's can only be fully understood and addressed with the expertise of specialist colorectal surgeons and teams who manage pelvic floor problems.

Thankfully, Nita had the confidence to seek expert advice when it was needed most. Hopefully, in raising awareness of these rare but extremely challenging perinatal injuries, Nita's story may help other women in similar situations to find the most appropriate care possible, as quickly as possible.

Women who have suffered trauma during childbirth can also contact the charity MASIC for support. www.masic.org.uk

**Nita is a pseudonym which has been requested by the person featured*

Celebrating the Romanian Ostomy Patients Support Foundation (ROPSF)

Bob Bailey, ROPSF 's Former Project Director and Chair

For almost 30 years, Bob Bailey and many others have supported ostomates in the Eastern European country of Romania, with the help of Colostomy UK. Here, Bob reminisces on how ROPSF came to be.

Imagine what it must have been like for ostomy patients in many parts of Romania to have undergone stoma surgery, even in the mid-nineties, knowing that the only ostomy appliances available were adapted plastic shopping bags, or if lucky, very rudimentary ostomy bags. There were no stoma care nurses, many of the hospitals were of a bygone age, and personal privacy barely existed.

Surgeons from the UK and other countries had been instrumental in training their colleagues in Romania. The standards of surgical intervention were recognised as good, but aftercare was lacking. In fact, it presented a serious shortcoming. There seemed also to be a disconnect between the patients' needs and the Romanian national health service's appreciation of patients' needs. In all, alarming and dispiriting for the patients and those supporting them; there was no health insurance or any other financial support. Added to which, patients regularly presented with cancer of the bowel at a late stage and the prognosis all too often became terminal.

But things changed following Sir Miles Irving's presentation to the Ileostomy Association in 1996, when it was suggested that UK ostomy patients might offer help to patients and the medical profession in Romania. The idea was seized upon and soon after the start of the project it became apparent that the vast majority of stoma patients had had surgery for bowel cancer - most probably linked to diet and smoking.

As the project developed, a decision was taken in 2000 to stand aside from the two principal charities, IA and the British Colostomy Association (now Colostomy UK) and set up an independent charity, namely, the Romanian Ostomy Patients Support Foundation (ROPSF). Although the charity stood as a separate body throughout, the two underlying charities and their members have always been most supportive, as have the UK stoma care nurses, colorectal surgeons from the Royal Colleges, as well as ostomy appliance manufacturers.

In Romania, it was fortunate that we were introduced to a select group of surgeons and nurses who supported the project and opened many doors in order for the ROPSF team to provide our support. Initially, we supplied surplus appliances, and trained nurses in basic stoma care, who later became trainers in their own right. Many Romanian nurses came to the UK where they were taught by highly professional nurse-trainers. Some spent time shadowing UK stoma care nurses in major hospitals. Alongside this, several patient support groups were also established across Romania.

> **In pursuit of more advanced training, several Romanians visited UK colorectal surgical units, and UK surgeons and nurses, as well as patients, spoke at Romanian surgical conferences, including the annual paediatric surgeons conference in Bucharest.**

Today, almost thirty years on, Romanian patients can expect better, reliable stoma equipment and greatly enhanced aftercare. Hopefully, with more advanced surgical techniques and earlier diagnosis, life expectancy is greatly improved with patients returning to a more normal, manageable lifestyle. The project has in numerous ways achieved the aim of raising standards in colorectal support and patient care.

Colostomy UK

Please support Colostomy UK

Whether it's a most welcome one-off gift or a much-appreciated regular direct debit donation (please see overleaf), your support makes a real difference. Thank you!

SCAN HERE TO DONATE

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

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

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Please ensure you also complete the 'My Details' section above

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☐ Other amount (please state) £

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

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Card number *(Maestro only)*

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

Signed Date D D M M Y Y

If you are a UK tax payer, please add gift aid to your donation at no cost to you.

giftaid it **Thank you for your gift** T77

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: / / 2025

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.)

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

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

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

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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.

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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.

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- 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.

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!

Saving Shots with a Stoma: Jake's Story of Football

BY OLIVER HOLMES

14-year-old Jake Cassidy has been a rising star in both professional and disability football teams, as well as receiving accolades for his work around stoma awareness. So, he's the perfect fit for this issue's Young Persons special.

In keeping with this theme, Jake was interviewed by fellow 14-year-old, Oliver Holmes, who has been volunteering with Colostomy UK as part of his Duke of Edinburgh Award.

Here, the equally football-mad Oliver tells Jake's story.

By day, Jake is a normal schoolboy living in Stoke, but it is on the football pitch that he really comes alive, playing in goal for both Stoke City's disability team and City of Stoke FC. Despite the confusingly similar names, the clubs are in fact very separate entities - the former is a professional side, and the latter is semi-professional.

Jake once hoped to become a professional footballer, but his plans were sidetracked when he was admitted to hospital at ten years old due to problems with his large intestine. His doctors suspected Crohn's disease but were unable to provide an official diagnosis.

Jake originally had an antegrade continence enema stoma (or 'ACE stoma') formed. An ACE allows for the delivery of enemas directly into the colon to help evacuate stool. These are more common in children because some underlying conditions relate to a child's physical development, and early intervention with an ACE stoma can prevent longer-term issues. However, Jake suffered from repeated infections, and his bowels became impacted, requiring manual evacuation, oral tablets to cleanse his bowels, and hospital visits nearly every six weeks.

After six months, it was decided that Jake's ACE wasn't working, and so his doctors decided he needed to have a colostomy. But four months later, Jake still hadn't had the surgery, as tests found that the blockages were higher in his intestine than where his colostomy would be, meaning it wouldn't work. As such, the only option was an ileostomy, which Jake had formed at the age of 11.

Up to this point, Jake played a prominent role in a pre-academy football club as their star goalkeeper. However, after being admitted to hospital, the club decided to let him go, citing Jake's 'unreliability' when he couldn't attend sessions consistently. Jake was understandably disappointed by this decision, but he says that it made him more determined than ever to start playing football again.

> **Jake was training at the Stoke City Goalkeeping Advanced Training Centre whilst getting ready for match level football. Yet despite this, multiple teams either rejected him or ignored him. Jake said that it was "annoying and upsetting" that no-one would let him play the game he loved so much due to his stoma. But after a few months of searching, a kind member of the public reached out to City of Stoke FC after hearing of Jake's struggles, and the club welcomed him with open arms.**

On the pitch, Jake uses a support belt and shield to protect his stoma . Even though the belt is designed to keep a stoma bag safe, Jake says that there have been a few times where - after a particularly rough collision - his bag has split open. He has measures in place to deal with this though: he always has spare kit with him, so he is able to quickly change, and there is always another player on the team that will go in goal until Jake is ready to come back onto the pitch.

Jake's manager, David, also sent out a message to all the other teams and referees in his league to make them aware of Jake's stoma, so he is always able to play. Given some of the risks involved, a lot of young people might feel daunted by the prospect of getting back onto the pitch, but there is little that can deter Jake from living life to the full.

In fact, Jake was recently awarded BBC Radio Stoke's 'Make A Difference Award for Bravery' by Ex-SAS Patrol Commander, Melvyn Downes. He won the award because of his status on social media, his fundraising, for helping the older generation around his area, and his determination in the face of his condition to live his best life.

Jake's bravery also shone through when, during the heatwave of summer 2022, he set out to climb Yr Wyddfa (formerly known as Mount Snowdon), just six months after having his ileostomy formed. Jake needed a lot of water due to his ileostomy, and this became more and more difficult to manage as they went further up the mountain.

Jake and his group made a valiant effort, but he was advised to stop and take a break by everyone around him. Jake's mother, Danielle, shared that you could clearly see that he was dehydrated, and he shouldn't keep going. "Everyone was telling him to go back, because he would need be rescued if he carried on."

Still Jake persisted, as luckily for him, passers-by told him about a river nearby he could go to for water. It was lovely and cold, and the team dipped their hats in the stream to try keep themselves refreshed on the climb. As the air got thinner, however, the walk up became increasingly difficult, and Jake started to feel worse the higher he went. Eventually, he was forced to abandon the attempt. Despite this setback, Jake plans to attempt the summit again later this year*.

Whilst on the pitch and in situations such as these, Jake calls his stoma 'Bob'. He does this to be discreet about his ileostomy. All of Jake's friends and family know to call his stoma 'Bob', so instead of having to explain any medical issues or face curious stares, Jake can simply refer to 'Bob' and everyone he's with knows he needs to find a private place to see to his stoma.

'Bob' is named after the popular children's TV character, SpongeBob SquarePants. This is because colostomy bags are "kind of spongey", like SpongeBob is himself, Jake explained.

It's no surprise that Jake chose such a comical name as SpongeBob for his stoma, as this is in keeping with his light-hearted attitude in general. Whether it be football, climbing mountains or overcoming issues with his health, Jake's positivity has kept him winning at life.

*Jake was lucky to find fresh water when he did! Colostomy UK would always advise listening to your body's needs whenever undertaking any form of strenuous activity or exercise. Ensure you carry plenty of water with you on such occasions too.

New ostomates may also wish to consult their stoma nurse before taking on any physical challenge.

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

Colostomy UK

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

Colostomy UK

#StomaAware

More information

ColostomyUK.org/StomaAware

What is a Stoma?

A stoma is a surgically-created opening in the abdomen. It diverts the flow of bodily waste from a damaged or non-functioning bowel and/or bladder, allowing it to be collected in a bag.

*A stoma can be temporary or permanent

There are three main types of stoma:

Colostomy	Ileostomy	Urostomy	
Diverts faeces from the colon	Diverts faeces from the small intestine	Diverts urine away from the bladder	A person wears a bag on their abdomen to collect bodily waste

200,000 People in the UK have a stoma

Who has a Stoma?

Anyone can have a stoma.

Why do I need to be Stoma Aware?

Empower people to access the information and Support they need.

To stop **Prejudice** and **discrimination.**

Not all disabilities are visible

#stomafriendly

Why do people need a stoma?

- Diverticulitis
- Cancer
- Crohn's & Colitis
- Childbirth
- Endometriosis
- Trauma
- Medical Negligence

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

…s to … safe and easy.

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

Why make your toilets stoma friendly?

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

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

The stoma friendly toilet

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

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

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

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

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

Not all disabilities are visible

For More Information and Free Stickers
T: 0118 939 1537 W: www.ColostomyUK.org
E: info@ColostomyUK.org Charity No: 1113471

Colostomy UK

Tidings Joins the Digital Revolution!

Over the coming months, we will be encouraging our readership to move away from the traditional paper copy of Tidings in favour of the online version of the magazine. In this article we explain why we see the change as necessary.

WHAT'S HAPPENING?

Most people currently receive a physical copy of Tidings by post. It's our hope that in the months ahead, these readers will move away from the paper copy of the magazine and opt for the online, digital version of Tidings instead.

WHAT'S PROMPTED THIS DRIVE TOWARDS DIGITAL TIDINGS?

The reason we are now asking most readers to move to digital is because we are having to keep a very close eye on our finances.

The move to a digital format will save us significant costs on printing and postage (which costs around £21,000 per edition).

These savings will help us to safeguard Tidings and the charity's future beyond 2025.

ISN'T THERE ALREADY A DIGITAL VERSION OF THE MAGAZINE AVAILABLE?

Yes! An online version of Tidings has been available for years. The back catalogue can be found on our website - simply search for 'Colostomy UK Tidings magazine' in your web browser.

Our past issues are a treasure trove of helpful information and fascinating stories.

WHAT ARE THE BENEFITS OF MOVING TO THE DIGITAL FORMAT OF TIDINGS?

There are lots of perks to receiving the online version of the magazine:

1. **Environmentally friendly:** By going paperless, we're drastically reducing our environmental impact.
2. **Accessible anytime:** Read the magazine on your phone, tablet, laptop or desktop computer, wherever you are.
3. **Immediate Access:** No more waiting for the post to arrive; enjoy each issue a week or two before it is released as a hardcopy.
4. **Interactive Features:** Embedded hyperlinks and videos mean that readers will be able to easily find other websites and online information referenced in the magazine.
5. **Supporting Colostomy UK:** The savings from postage and print costs will help us provide more resources and services for the stoma community.

I'M STILL HESITANT ABOUT SWITCHING TO THE DIGITAL VERSION OF THE MAGAZINE.

That's completely understandable. We know change can be daunting for some.

We're also aware that some of our readers might not feel comfortable using the internet, or might not have regular access to a computer, smartphone or laptop.

If you have any of these concerns, please don't hesitate to call us on our admin line to see how we can help:

0118 939 1537 (Monday to Friday, from 9am to 5pm)

You can also refer to the FAQs on our website, which will give you much more information about the change: Simply search for 'Colostomy UK Tidings FAQs' in your web browser.

I'M HAPPY TO GIVE THE ONLINE VERSION OF TIDINGS A TRY. WHERE DO I SIGN UP?

To move to digital Tidings, you can:

- Call us on our admin line on: 0118 939 1537 (Monday to Friday, from 9am to 5pm)
- Alternatively, if you have a smartphone you can scan the QR code below which will send you through to a short form to complete.

Thanks in advance to everyone willing to give digital Tidings a chance.

We know it will be a big change for some, so we really appreciate your willingness to help Colostomy UK with this initiative!

Zeppy the Stoma

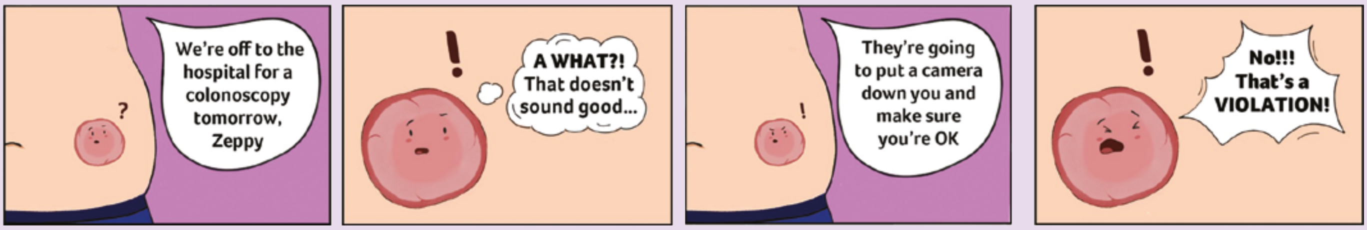
Zeppy the Stoma is the creation of Stewart Russell. Artwork by Emily Crowley

This edition's comic strip is dedicated to Zeppy's creator, Stewart Russell, who sadly passed away on the 26th of November 2024. Here we bring you the last story that Stewart contributed to Tidings.

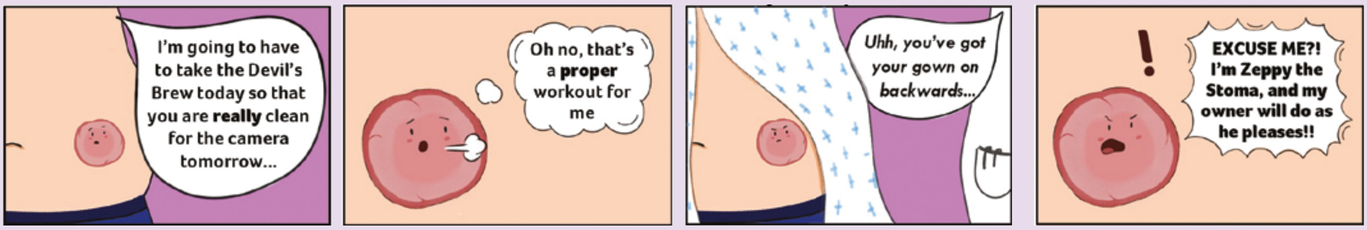
We will always be grateful for the laughter and joy Stewart brought to so ostomates, first through 'The Adventures of Zeppy' posted on Colostomy UK's Facebook Group, and later here in the pages of Tidings.

Warm, playful, and creative, the whole team at Colostomy UK, and particularly those on the Editorial Team, will miss Stewart dearly.

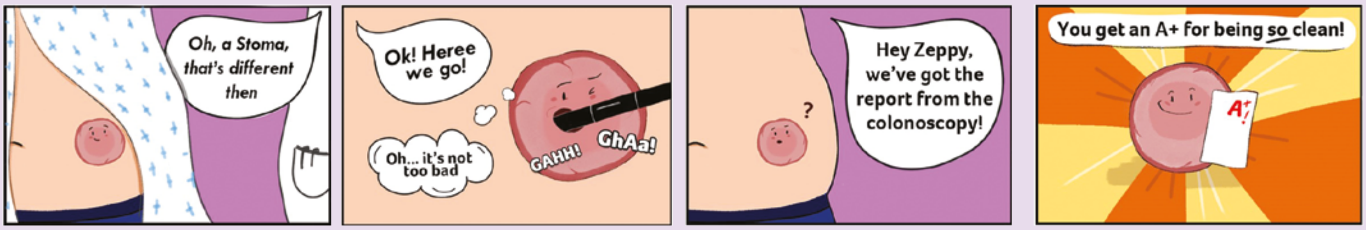
It was Stewart's wish that the comic should continue bringing light relief to readers, and so his memory will live on through Zeppy's future adventures. We promise to do him proud.



The next day at the hospital...



A week later...



Stewart's Advice:

Anal colonoscopies are notoriously very uncomfortable experiences. Via the stoma it is a reassuringly much easier procedure. Zeppy's owner had mild sedation for his, and was able to watch it on the TV screen. The "dignity shorts" were a pair of extremely baggy blue paper shorts, quite where "dignity" came into it… well, at least they were amusing. Colonoscopies through stomas are relatively infrequent events for the nursing staff, who therefore often assume that like everyone else your gown should be open at the back and that you should lie on your side – no, that's not how we do it!

Team Colostomy UK Rugby League Update

Giovanni Cinque
Marketing & Campaigns Manager
GetInvolved@ColostomyUK.org

During the working day, Giovanni Cinque is Colostomy UK's Marketing and Campaigns Manager. But come the weekend, he commits himself to his first love, Colostomy UK's Rugby League teams. Here he gives a round-up of 2024.

Our Rugby League season came to an end in November with two consecutive trips to Wales.

First up, on November 16th, our **Wheelchair team, Purps on Wheels,** paid a visit to Deeside, the home of North Wales Crusaders.

For readers that don't know it, wheelchair rugby league is genuinely the most inclusive sport of all – not solely a disability sport, as non-disabled people are welcome to compete as well, and both men and women of all ages can play in the same team.

A competitive game played in good spirits, ended in a 66 - 22 win for the Crusaders.

It was game number five for the team following earlier fixtures against Brentwood Eels, Gravesend Dynamite, Sheffield Eagles, and Woodland Warriors. A really steep learning curve for a squad which, prior to this year, had never played wheelchair rugby league. The team also can't train together due to the geographical spread of our players, so they've done incredibly against the odds.

Everyone is really looking forward to returning in 2025, and this will be with our own wheelchairs, having received the brilliant news that a grant application to Sport England was approved. The previous year we had been borrowing wheelchairs from our opponents.

The grant will make a huge difference to how quickly we can grow and develop as a team.

The following weekend, our **Physical Disability Rugby League** (PDRL) team headed to Port Talbot in South Wales to end their season with a game against Aberavon Fighting Irish. The Aberavon club are very good friends of ours and there is a large cross over of players who represent both teams.

Unfortunately, the game took place over the weekend that Storm Bert hit the UK, with the south of Wales particularly badly hit. Our game survived, but only while playing under modified contact rules. It was a fun, but low-key end to another groundbreaking season, that saw us beat the Leeds Rhinos PDRL team and graced the hallowed turf of the 'House of Pain' - Sardis Road in Pontypridd, where we triumphed over the Wales PDRL team. We also fielded four teams for the first time at our 'Big Day Out' with Sheffield Eagles in July and played in front of over 3,500 people before Widnes Vikings played Toulouse.

Following the game with Aberavon Fighting Irish we held our end of season dinner and awards. The awards are an opportunity for the players to reflect on the season together and reward those who excelled both on and off the pitch.

This year's winners were as follows.

Wheelchair Player of the year
Tim Cree

PDRL Player of the year
Matt Turner

Best newcomer
Becca Cree

Club person of the year
Tim Cree

Outstanding achievement
Giovanni Cinque

The 2025 season for both our Wheelchair and Physical Disability Rugby League teams will kick off in February, and we are always on the look-out for new players, helpers and supporters.

Please get in touch with Giovanni if you'd like to join us at Giovanni.cinque@colostomyuk.org. You'll be sure of a very warm welcome.

Step Up for the over 200,000 people in the UK living with stomas, by getting active this April and take on our 200,000-step challenge! Whether you run, jog, walk, skip, swim or roll, there are many ways you could Get Active and raise vital funds for Colostomy UK. Not an avid stepper? Take on an active challenge of your choosing.

Why Step Up for Stomas, Active April?

It is no secret that getting active is beneficial for both your physical and mental health - reducing anxiety, boosting self-esteem and helping you to become physically healthier. No fancy equipment or gym membership is needed – as long as you have an active challenge that is suited to your abilities, you can take part in Step Up for Stomas Active April and help us to support anyone impacted by a stoma in the UK, making this challenge not only beneficial for you but for thousands of others too.

How Can I Get Active and Take Part?

There are many ways to take part in this year's Step Up for Stomas, Active April challenge!

Walking 200,000 steps over the month (that's 6,600 steps a day), one step for every person who could benefit from our support. You could do this as a solo challenge or as part of a group and share the steps/distance!

If steps aren't for you, get creative and take on any active challenge of your choosing - for example:

- Commit to doing 200 squats, lunges or crunches every day in April
- Stretch yourself with 200 minutes of Pilates or yoga each week (that's less than half an hour a day)
- Enjoy a 20-minute daily walk, swim or dance

For more ideas on how to take part in Active April head over to our website!

www.colostomyuk.org/get-involved/activeapril

How your fundraising helps:

As a self-funded charity, every £1 that we raise really does make the world of difference. As part of this challenge, we would love it if you could aim to fundraise as much as you can – setting a target of £200 or £2000 may be helpful!

Your fundraising efforts will allow us to support thousands of people around the UK before and after stoma surgery. Thanks to our Step Up participants, we will be able to continue providing our 24-hour stoma helpline, private Facebook group and Tidings magazine free of charge. We will also be able to continue to produce our wide range of support literature, run care workshops and campaign for a more Stoma Aware UK.

1

Register online

Register online at **www.colostomyuk.org/getinvolved/activeapril**. It's free and easy to join.

2

Choose your challenge

200,000 steps in April breaks down to only 6,600 a day – does that sound more achievable?

We also encourage you to get creative if steps aren't for you - why not create your own challenge around the number 200? 200 minutes of an activity in a week is just under half an hour every day. There are plenty more ideas over on our website!

3

Kickstart your fundraising

You can set up your Active April fundraising page on JustGiving or Facebook – you can also use our sponsorship form available to download from our website **www.colostomyuk.org/get-involved/activeapril**

justgiving.com/campaign/sufs-active-april
facebook.com/colostomyuk

4

Set yourself a fundraising target

Whether it is focussed on the number 200 or 2,000 or a target of your choosing, having a goal is likely to help you generate more support.

5

Tell everyone!!

Share your intention to Get Active in April with everyone you know, and don't be afraid to ask people to sponsor you or join in – remember you are not doing it for you, but to help the over 200,000 people in the UK living with stomas get the support they need.

6

Order now

Pre-order your Step Up for Stomas, Active April merchandise before Monday 10th of March. Order now over on **www.colostomyuk.bigcartel.com/**

Quotes from previous participants:

"I took on the 7K step challenge. I pushed myself to complete my walk before work each morning, therefore some early starts were involved. I wanted to feel the change I was making and in a very small way mirror that discipline of change mindset that ostomates have no choice but to make."

"The benefits that I personally got out of being part of Step Up for Stomas were quite simply, the pleasure of getting sponsored by many of my friends and family for doing something active that I loved and enjoyed doing. It made me feel that I was at last doing something constructive to repay in some small way, the charity and surgery that actually gave me my life back".

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 or by calling 0344 879 4417.

Young Persons Q&A

Here, two young ostomates tell us how they feel about living with their stomas, as well as some of the incredible things they've achieved within their first decade on earth.

Hunter Garrod
9 Years old
(Written with support from mum, Cody)

Jack Dale
9 Years old
(Written with support from mum, Zoe)

Hunter Garrod

When and why did you have your stoma formed?

I have a stoma due to our local hospital leaving me for 8 years on laxatives and just saying I was 'constipated' and that I would grow out of it. They refused any tests, even though I had a large, impacted stomach, bags under my eyes, and was very frail/skinny. Eventually we referred ourselves to Great Ormond Street Hospital where a test showed the left side of my colon wasn't working, which is why I had to have the stoma formed.

What's been the best thing about having a stoma?

I am no longer in pain. I can do everything a 'normal' person my age can do. I am as fit as ever and can do all my sports (football, boxing, swimming and running).

What's been the most challenging thing about having a stoma?

When we go on holiday in hot countries, sometimes my bag doesn't stick, so it keeps falling off in the water due to the weather and chlorine*.

What stoma-related activities have you been involved in?

I have raised over £500 for Colostomy UK when I did 'Step Up for Stomas'. I also raised £115.99 for 'Guts UK'.

I also attended 'Dancing on Ice' with Adele Roberts and was on BBC Breakfast talking about my stoma. I am an ambassador for Salts Health Care and have supported the Colostomy UK rugby team.

What incentivised you to do the particular activities you've been involved in?

I enjoy meeting new people and when I go to these events, I get to meet people just like me, with stomas!

What have been the highlights of the things you've been involved in?

Meeting a range of different people with stomas, not being in pain anymore, raising money for charity and seeing myself on the TV!

Do you have any plans for more stoma-related activities in the future?

I would love to be involved in making an action figure with a stoma bag just like me!

Hunter and his mum Cody

Hunter's final thoughts

Having a stoma feels very scary, but the only thing that scared me was being put to sleep before my operation! Now I have my stoma I am free from pain and can be happy again!

* Top tip – putting roll-on deodorant onto the skin under the bag can prevent this!

Jack Dale

When and why did you have your stoma formed?

My stoma was formed due to chronic constipation in January 2022. Since I was a baby, I have suffered with bowel issues which have stopped me having normal bowel movements.

What's been the best thing about having a stoma?

Not having to be in hospital a lot and being able to enjoy my sports again.

What's been the most challenging thing about having a stoma?

Having to deal with a prolapsing stoma quite a lot, as you don't know when this is going to happen.

What stoma-related activities have you been involved in?

I've promoted Stoma Awareness Day at school and also got lots of community grassroots football teams wearing stoma-aware purple bands. This helps everyone understand that some of us live with a bag.

I've taken on lots of fundraising challenges too, including walking one mile a day for 30 days, a 50-mile triathlon, and a 13-mile walk from the village of Shotton Colliery to the Stadium of Light (Sunderland F.C. Football Ground).

I like raising awareness of living life with a stoma and letting everyone know we have a hidden superpower!

What incentivised you to do the particular activities you've been involved in?

I wanted to spread awareness and to help everyone to not be scared of living life with a stoma, as we are not different to anyone else. We just have a hidden superpower.

What have been the highlights of the things you've been involved in?

Being on the news and spreading awareness to the wider world. Also, definitely doing Stoma Awareness Days at school to spread awareness to all of my friends.

Do you have any plans for more stoma-related activities in the future?

I want to climb a mountain to raise more funds and to carry on spreading awareness to the wider world that living with a stoma is a superpower. No-one should be treated differently just because they have a disability.

Jack's final thoughts

My stoma has helped me to carry on being a normal 9-year-old and to complete the activities I love, including football, swimming and playing with my friends.

*Introducing...*The Well-being Hub

At Salts Healthcare, well-being is at the heart of everything we do. We focus on five key pillars of well-being which we believe are essential for a happy and healthy life.

Our new well-being hub provides *a supportive and empowering online community* where you can access the latest well-being content, resources and expert advice in one central space. Here you can find:

- Helpful information that promotes positive well-being whilst living with a stoma.
- A wealth of resources to help support your well-being.
- A supportive community space where you can explore different journeys and the Salts Healthcare Advocate community.
- A dedicated area for you to get involved and have your say. You can participate and contribute to the community, share your ideas and experiences.

Scan the QR code to find out more or visit www.salts.co.uk

salts HEALTHCARE

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

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dear nurse

Finding the Perfect Stoma Products

As our Campaigns article (page 6) highlights, the number of stoma care products that patients can easily choose from via the NHS is likely to increase in the coming years. But choice can also be bewildering! Stoma Care Nurse, Helen Disley, offers advice on finding the perfect stoma products for your personal needs, in partnership with SecuriCare.

There are so many different stoma products on the market. Manufacturers are constantly updating and innovating new product ranges, which is great for the consumer but can make choice overwhelming, especially for new ostomates.

In the early days after surgery, your Stoma Care Nurse will use their expertise and clinical judgement to help you find the most appropriate products for your needs. Achieving a good seal to the skin is top priority when choosing the correct bag, to reduce the risk of leakage and sore skin. Pouch security and comfort are vital during that early adjustment phase to help ostomates develop confidence and speed their journey towards acceptance.

The ability for an ostomate to browse or try different products is now easier than ever with social media and online sampling. Once you've recovered from your surgery and are resuming normal activities, you may wish to have a look at alternative appliances, so here is an overview of pouch features to look out for and compare, to help you find the right one for you.

BAG SIZE

Most pouch ranges come in various capacity sizes (usually 'mini', 'midi' and 'maxi'). While the standard 'midi' size suits most, smaller sized people may prefer a smaller pouch. The 'mini' appliances may also be worn for swimming or intimate moments (bearing in mind that capacity will be reduced so the appliance may need emptying more frequently). A larger size can be useful for travelling or overnight.

BASEPLATE (AKA 'FLANGE') SHAPE

We are all different shapes and sizes so you may wish to choose a baseplate that best fits your individual body shape. Convex shaped baseplates are useful for poorly spouted stomas and concave pouches for those with outward body shapes such as parastomal hernias. There are also baseplates in different sizes, or with petalled edges that can mould better to your shape, especially if the skin contours around the stoma are uneven.

BASEPLATE ADHESIVE

Manufacturers have modified the adhesives too, many have added skin friendly properties such as Manuka honey, aloe vera or vitamin E. So, if you find an appliance causes irritation, you may prefer to try a product from a different range.

FILTER

Some ostomates experience ballooning of their stoma appliance (when the bag fills with air). Although dietary adjustments may help to reduce ballooning, it may also be helpful to try a pouch with a different filter.

FABRIC COVER

The fabric covers of stoma appliances are now available in various textures and with a choice of colours too. This is very much a personal choice, so you may wish to look at alternative black, grey or white covers, which are designed to coordinate better with your clothing/underwear and make you feel more confident.

FLUSHABLE BAGS

Flushable stoma bags are a convenient way of managing your colostomy, especially when travelling or at work.

1-PIECE VS 2-PIECE

1-piece ranges (where the bag and baseplate are permanently attached to each other) are more commonly chosen by ostomates because of their baseplate flexibility and low profile. However, newer 2-piece ranges (where the bag and baseplate are separate and then attach together), are much less rigid than they used to be, and are now easier to put together. The baseplate can remain in place for 2 - 3 days, providing the option to change the pouch without the need to clean and prepare the skin each time. It's a balancing act between comfort and convenience which, once again, is down to personal choice.

ACCESSORIES

Various accessory products can be used to protect the skin, prevent leaks, aid bag security and increase comfort. These include powders, washers, pastes and baseplate extenders. Other accessories include deodorants, lubricating gels and stool thickeners. Discussion with your Stoma Care Nurse will help target your search for a suitable accessory product depending on your individual concerns or management issues.

It is advisable to wear a hernia support belt for sporting activities, and you may use a stoma shield to protect the stoma during contact sports.

Summary

It is fantastic that there is so much choice – but please ask your Stoma Care Nurse (or stoma supplier) for guidance if you would like to try a new stoma bag or accessory. They can provide appropriate samples from the many different ranges available, which will help you to find your perfect products.

Your Letters and Emails

Most of the letters and emails we highlight come to us via the Editorial email address (editor@colostomyuk.org). But our staff and volunteers also receive fascinating queries from ostomates and often reply with invaluable information. Here, we share a couple of questions received via our helpline and support inbox, as well as well as our team's helpful answers.

Hi,

Does Colostomy UK receive any feedback from members about their water bills? I am a long term ostomist (1977) but I had surgery in 2021 which left me with a new, higher output stoma. This has led to requiring more frequent emptying and often repeated flushing to fully clear the toilet bowl. During the same period I have seen a significant jump in my metered water charges and was wondering whether this was a just a coincidence!

Best wishes,

Alan Milne, Wirral, Merseyside.

J.

Our Volunteer and Support Coordinator, Jo McKenzie, came back with some very sound advice for Alan, which we're sure many readers might benefit from in these financially challenging times

All water companies in the UK offer discount schemes for people who use more water than average due to medical conditions.

The scheme is called WaterSure and is available across England and Wales.

Eligible medical conditions include:

- Abdominal stoma
- Crohn's disease / ulcerative colitis
- Desquamation (flaky skin disease)
- Eczema, psoriasis, or varicose ulceration (weeping skin disease)
- Incontinence
- Renal conditions requiring home dialysis (except where the NHS contributes to water costs)
- Any other medical conditions that require extra water

You must also be in receipt of one or more state benefits to qualify, though these vary depending on your water provider.

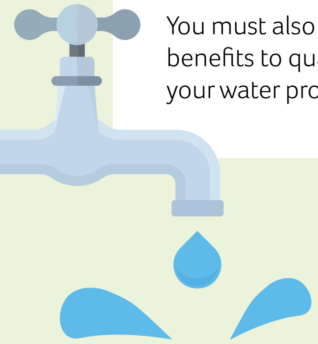
You can find more information via the Citizens Advice website, or simply search for 'WaterSure Scheme' through your internet browser.

In Scotland, Scottish Water offers a Priority Services Register for customers who may need additional assistance due to disabilities, medical conditions, or other special circumstances (this service is also available in other parts of the UK). While this register doesn't provide direct financial assistance, it ensures vulnerable customers receive priority support during water-related emergencies or service interruptions.

Northern Ireland Water does not offer a scheme directly comparable to WaterSure. Water charges are currently included in rates payments, rather than being billed separately, meaning that most households do not receive a separate water bill.

Customers in Scotland and Northern Ireland should therefore contact their respective water providers to discuss available options for support:

- For Scottish Water, search for Priority Services Register
- Northern Ireland Water's website is www.niwater.com



Hello there,

I wondered if you have any information about access to disability toilets in France. I know that there is a Euro-key, which is the equivalent of UK Radar keys. However, as far as I can find out, there is solely one company in Germany which supplies them, and it no longer ships them to the UK because of the regulations and cost since Brexit. I am not even sure if France is one of the countries in the scheme.

We have a house in France and will be going there in three weeks' time for the first time since my colostomy last September. I'm slightly concerned about the 8-hour journey once we land in France!

Warm wishes

Anne Stokes

Our volunteer, Debs, who dealt with the query, found the following advice to share with Anne

It's unfortunately true that UK radar keys don't work outside of Great Britain, so people living with a stoma need to find an alternative when traveling in Europe.

On the continent, there is an equivalent to the radar key called a 'Euro-key', which is manufactured in Germany, but it does have a couple of limitations.

Firstly, as Anne points out, the Euro-Key can no longer be sent to the UK. An alternative may be to use an address in Europe, such as that of an B&B, a friend's house, or a holiday home, if you have one. But it can take up to a month for the key to arrive, so forward planning is crucial!

Secondly, the Euro-key is only available in a handful of countries, namely, Germany, the Netherlands, Austria, Switzerland, the Czech Republic, and Slovakia. So not very useful for France, where Anne is travelling to!

Thankfully, the Disabled Accessible Travel Website has a great app available on smartphones, called 'Accessaloo', which highlights accessible toilets all over Europe.

Thanks must go to the Mobility Scheme website which provided much of the above information.

Regular readers of this column will know that over the past few issues, we have covered a number of emails regarding the Braun IryPump. This electronic irrigation system is a lifeline for many ostomates, so there has been great concern over the fact that Braun has stopped manufacturing the device. John Metcalfe previously gave great advice on how to fix the pump yourself, but for those who don't feel confident with a screwdriver, Mike Amura has found what may be the perfect solution.

Hi Ross,

I struck lucky last week and found a company who specialise in electronic repairs and micro soldering. The company is called Elecfix and is run by a chap called Mark, based in Cornwall.

Their IryPump service is £49.99. This gives you a full service and replacement filters. Then you choose to fix anything else that's broken and add that to the purchase.

My control knob had broken internally, so service was £49.99, plus £10 for the controller repair, £59.99. All done and back with me in 4 days!!

Mark is professional and very knowledgeable.
He understands how important the pump is to users.

I feel very relieved now I know I have him to refer to for issues moving forward.

Details are as follows:
Email info@elecfix.biz
Phone: 0777965425

Kind regards ,

Mike

Something you'd like to share with the community? Why not get in touch.

You can email us at: **editor@colostomyuk.org** or write a letter to us at:

The Editor, Colostomy UK, 100 Berkshire Place, Winnersh, Wokingham, Berkshire, RG41 5RD.

Please also say if you're happy for us to use your first or full name. If we don't receive permission to use your name, we will use your initials only. Happy writing!

For general queries you can contact our helpline on: **0800 328 4257** or support email address **hello@colostomyuk.org**

Support Group News

Here we catch up on the progress made by Stoma Support Groups.

Castlepoint Stoma Support Group, Essex

In the previous Winter 2024 edition of Tidings, we featured a new Support Group based in Castlepoint, Essex. Since then they've gone from strength to strength, as Sally Wood explains

Castlepoint in south Essex is made up of four towns - Canvey Island, Hadleigh, South Benfleet and Thundersley.

Our local supermarket has a community room which can hold up to 20 people, so this became our first premises. We advertised online as well as leaflets in places like GP surgeries.

The stoma nurses at Southend Hospital were a Godsend too, putting our leaflets in all their appointment letters and in the new patient packs.

We soon went from 11 attendees to 22, but this then gave us the problem of needing a new premises, but we didn't have any money to fund this, despite an appeal on BBC Radio Essex!

Eventually we managed to secure a church hall in Benfleet. Each month we have a guest (we recently had a Personal Trainer attend to discuss tummy exercises) and activities such as quizzes.

We now have 35 members, and we can't wait to see how we grow in 2025!

Meets: 1st Tuesday of every month. 10.00 am - 12.00pm

Where: St George's Church Hall, Rushbottom Lane, Benfleet, SS7 4DN

Contact: Sally Wood'

Email: sallywood03@hotmail.co.uk

Gloucester Ostomates, Gloucestershire

Julie Davies talks through her experience of recently setting up Gloucester Ostomates

For a long time, I wanted to start a group and when I was forced to retire from work on medical grounds in 2023, it gave me the push (and the time!) to finally get one up and running.

When the group started, we had just one member, and now it has grown to 11, and ages range from 27 to 90! The group is open to anyone who has or might need a stoma, and anyone who supports someone with a stoma. We currently have two members with a urostomy, three with a colostomy, and six with ileostomy.

As well as weekly meetings, we have days out, and soon we hope to have evening meetings so that those working in the daytime can come along.

Meets: Every Friday, 10.30 am - midday

Where: The Irish Club, Horton Road, Gloucester, GL1 3QA

Contact: Julie Davies

Email: juliematthew@hotmail.com

Tel: 07979129001

Connect Harlow and District Stoma Group, Essex

Bryan Woodyatt of Connect Harlow and District Stoma Group also got back in touch to share highlights from their Christmas meet-up.

Everyone enjoyed the meal at the Canons Brook Golf Club in Harlow. The food was delicious, not least the Christmas pudding. Everyone is now on a diet!

Connect is a stoma and ileostomy support group that covers Harlow and the surrounding areas, with members in Ware, Sawbridgeworth, Waltham Abbey, Harlow, Essex and Hertfordshire. We often have speakers and entertainment. Come and join us!

Meets: Every 2nd Tuesday of the month. 10.30 - midday

Where: The Link Social Club, Parsloe Road, Harlow, CM19 4RT

Contact: Brian Woodyatt

Email: brian.woodyatt@btinternet.com

If you would like to share highlights about your own Support Group in Tidings, you can contact us via editor@colostomyuk.org

If you would like advice on setting up your own Support Group, you can contact Community Engagement Lead, Shauna Hemphill, on shauna.hemphill@colostomyuk.org

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)
Margaret Slucutt T: 07967102141

Buckinghamshire

High Wycombe Stoma Support Group
T: 0800 318965

Milton Keynes Stoma Support Group (MKSSG)
E: support@mkssg.org.uk
T: 07843 768386

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: 07980 432072
E: murphy.rowe781@btopenworld.com
Ceri Moore T: 07871926631
E: ceri.moore75@outlook.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 (Poole)
Jenny Pipe T: 01202 740 440

Essex

Castlepoint Stoma Support Group
Sally Wood
E: sallywood03@hotmail.co.uk

Connect Harlow and District Stoma Group
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

Gloucestershire

Gloucester Ostomates
Julie Matthew T: 07979129001
E: juliematthew@hotmail.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
Ian Gapp T: 07710288785
E: iangapp13@gmail.com

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

Hertfordshire

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

Stevenage Ostomistics
Judy Colston T: 0795 775 4237
E: neilcolston@btinternet.com

Isle of Wight

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

The Baguette Group
Debbie Lumley T: 01983 741384
E: debbieattwiggs@gmail.com

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
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

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

London

Bowel Cancer Support Group
Sue Berry T: 01737 553 134
John Amos T: 020 8668 0796
E: john.amos@sechc.org.uk

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

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: 07729 750622
E: becauseliverpool@gmail.com

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
Sandra Hutchings T: 01502 585 955

Kings Lynn Ostomy Friendship
Support Group
T: 01406 363756 or 01553 775698

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

Northamptonshire

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

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull T: 07714 479 320

Hexham Ostomy Group
Marie Douglas 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
Sally Jefferies
T: 01980 611978 or 07584 574311
E: info@wessex-stoma.co.uk
W: wessex-stoma.co.uk

Wirral

Wirral Stoma Support Group
T: 07956 216218

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

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

Ulster Hospital
Sarah, Jacqueline and Lisa.
The Colorectal Nurse Specialists
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

Angus

Dundee Stoma Support Group
E: Rachel.ferguson2@nhs.scot
T: 07581 797605

Edinburgh

Providing Ongoing Ostomate Support Scotland
E: info@poosscotland.co.uk
W: www.poosscotland.co.uk

Greater Glasgow

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

Moray

Moray Ostomates Support Group
Hazel T: 07926 300450
Kathleen T: 07789 684285

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

We need your support to Smash Social Exclusion

for people living with stomas

Be #StomaAware
Smash
Social Exclusion

Nobody should feel excluded from doing the normal things in life, like going to the shops, having a coffee with friends or watching a football match at their local stadium.

To donate, scan this QR code

Visit www.colostomyuk.org/donate or go to page 27 for our donation form

Be #StomaAware
Smash Social Exclusion

Colostomy UK

Colostomy UK Workshop: Caring for someone with a stoma

Our workshop provides unpaid carers, and health & social care professionals with practical advice and guidance on how to care for someone with **any type of stoma**.

By educating carers on the practical and emotional aspects of stoma care, we can directly improve the quality of life of those living with a stoma with additional support needs.

Virtual 2 hour workshop

Group or individual training

Facilitated by a qualified stoma nurse

Priced according to your organisation

Course overview:

- The basics of supporting a person with a stoma
- Understanding how stomas are formed
- Types of stoma bags and how to change them
- Stoma problems
- Patient worries and lifestyle adjustments
- Physical and psychological issues associated with having a stoma
- Q&A

> *I enjoyed the course thoroughly. I have some knowledge now of stomas and it will make me feel more confident when the situation arises. That's a huge step ahead!*
>
> **Social Care Reablement, Devon County Council**

> *I gained lots of information from taking part in this course, I will be more confident to care for a patient with stoma.*
>
> **Woodhayes Nursing Home**

Contact getinvolved@colostomyuk.org or call 0118 939 1537 to find out more