

Tidings

Supporting & empowering ostomates

“Be brave”

Lillie Dodd shares advice to others facing stoma surgery, while her mum, Emma, discusses autism, rare diseases, and stoma care.

Page 31



PAGE 34

Adhesions and blockages explained, by Colorectal Consultant, Mr Ian Daniels



PAGE 18

Trina Mant on the Power of Befriending

Real stories
Real people

Introducing the NEW Look CeraPlus™ Barrier Ring*

The introduction of Hollister's new barrier ring packaging significantly reduces plastic waste, furthering Hollister's commitment to sustainability practices and continuous progress**. The barrier ring products inside the packaging that you use and trust, will remain exactly the same.

Up to **60%** LESS PLASTIC**

Saving 4 plastic bottles per box



Ceramide-infused formulation

Supports healthy skin



Peelable tab

Designed to reclose for re-use

Refreshed look & name

Slimmer design

For improved discretion

Over **25%** SMALLER BOX**

For more efficient storage



Proudly taking a step toward a more sustainable future



Scan the QR code to request your sample today

*CeraPlus™ Skin Barriers contain the Remois Technology of Alcare Co., Ltd.

**Data on File 2025, packaging material analysis. Compared to previous Hollister packaging design.

Average calculated across Hollister barrier ring portfolio. Prior to use, be sure to read the Instructions for Use for information regarding Intended Use, Contraindications, Warnings, Precautions, and Instructions. Not all products are CE marked. All other trademarks and copyrights are the property of their respective owners. Hollister, the Hollister logo and CeraPlus are trademarks of Hollister Incorporated. ©2026 Hollister Incorporated.

For FREE samples call **0800 521 377 (UK)** or **1800 503 400 (IRE)**



CeraPlus™ Ostomy Products



Editorial Team

Editor, Writer & Researcher

Ross Othen-Reeves

CEO

Libby Herbert

Ostomate Volunteers

Jackie Dudley

Jillian Matthew

Holly Broomfield

Former Ostomate & Volunteer

Leslie Mello

Tidings Digital is identical to the physical copy of Tidings, but can be enjoyed on your laptop, tablet or smart phone.

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.



Tidings Magazine:

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

Disclaimer:

The display, description or demonstration of products and services or the inclusion of advertisements, inserts and samples within Tidings Magazine does not constitute an endorsement or recommendation of these products and services by Colostomy UK. ©Copyright 2026 Colostomy UK. All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, except as permitted by the UK Copyright, Designs and Patents Act 1988, without the prior written permission of the publisher. All marks acknowledged.

Design & Production

H2 Creative • Digital
www.h2.co.uk

WWW.COLOSTOMYUK.ORG

Dear readers

Welcome to this summer edition of Tidings. We made it! Long days and warmer nights are with us once again at last. It is also the season for marking various national awareness campaigns which are close to the hearts of many people living with a stoma.

This includes National Carer's Week (8th – 14th of June), which we've celebrated through a touching article between Ellie Wilkes and her beloved grandad, David Sims, who Ellie recently took on a caring role for.

In recognition of Loneliness Awareness Week (15th – 21st of June), Trina Mant reflects on the sense of isolation she felt following stoma surgery, and how Colostomy UK's Befriending Service played a vital role in alleviating these feelings.

Falling between the 11th – 17th of May, Mental Health Awareness Week would have just passed by the time this issue of Tidings arrives. We have honoured it regardless, knowing as we do that it's a subject that impacts many ostomates. Barbara Milleret offers professional yet compassionate advice on the topic in our regular Dear Nurse column.

Practical stoma advice also comes courtesy of Colostomy UK's President and Colorectal Consultant, Ian Daniels, who shares all there is to know on adhesions and blockages. Also within our Wellbeing section, ostomate Kev Harvey-Austen explains how life with a parastomal hernia has proved more challenging for him than living with the stoma itself. He also offers tips on how early intervention could help others avoid a similar experience.

Regular contributor, Jackie Dudley, recently underwent surgery for a health issue unrelated to her stoma, but her stoma went to hospital with her regardless of course! Jackie talks through how to best prepare for such an eventuality.

All of this and we've not even touched on the rich variety of Real-Life articles we have in store for you. Jo Prance shares the third and final installment of her proctectomy diaries, speaking candidly about where she's at six months on from surgery.

We begin a new series exploring the unique and surprising jobs to be found within the stoma community. Kicking things off, we hear from a member of the British Armed Forces stationed overseas.

Another globetrotter, Izzy (a pseudonym), talks powerfully about her experience of waking up from a medically induced coma to discover she had a stoma. Not only this, she had to learn to walk, talk, and feed herself again. But this seismic event was also an awakening for Izzy, who transformed from timid young person to adventurous adult who hasn't looked back since.

Mat Dean is another ostomate who saw his life turned upside due to a barrage of additional life-threatening complications. Thankfully, Mat's health slowly recovered, and he's been able to return to his primary passion of bodybuilding competitions. But with the aim of the game being physical perfection, Mat had to first face his fears over competing with his stoma bag and scars on display.

Last but not least is our cover feature, Lillie Dodd, whose story is shared largely by Lillie's mum, Emma. Lillie has a learning disability and autism, type 1 diabetes, a rare chromosomal condition, and not one, but two, stomas. Emma and Lillie don't pretend life isn't challenging at times, but this doesn't stop Lillie greeting every new day with her famous smile. It's as bright as a warm summers' day.

Ross Othen-Reeves
Editor, Writer and Researcher



Information and support for life with a stoma

Whether you are preparing for surgery, adjusting to life with a stoma, supporting someone you care about or working in healthcare, **our free literature is here to help.**

From practical guides and everyday advice to specialist information, you can browse our full range online, download PDFs or order printed copies **free of charge.**

Guides for every stage of life

Getting started
Helpful information before and after surgery.



Everyday living
Practical advice for day to day life, diet, travel, relationships and more.



Family and carers
Supporting someone with a stoma and looking after yourself.



Children and young people
Information and support for younger people and their families.



Scan to explore the full range



Browse, download or order your free copies

Health and treatment
Information about your health, treatment and managing symptoms.



And much more...

Irrigation, How will a Colostomy affect me, Colonoscopy through the stoma, Stoma Friendly Toilets, Travel Certificate, Ovarian Cancer and Stoma's, Welcome Packs and more.



Colostomy UK is a National Charity that exists to make a positive difference for anyone impacted by any kind of stoma or stoma surgery.

Founded in 1967, we became a registered charity in 2006, and we maintain our original mission to this day: to support people with stomas and those who care about them.

We:

- » Provide practical and emotional support and advice whenever it's needed.
- » Run projects that empower and build the confidence to take on fresh challenges.
- » Are a voice on the issues that matter, campaigning and advocating for ostomates' rights.

We want to live in a world where having a stoma presents no obstacles or barriers and carries no stigma.

A world where people can:

- » Get the right information and advice, at the right time, at the right stage of their stoma journey.
- » Have access to the facilities and resources they need when and where they need them.
- » Live their lives to the fullest without fear of discrimination or prejudice.

How to contact us

Stoma helpline for:
Emotional support, experience-based advice and guidance from a volunteer.
0800 328 4257
365 days a year 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:



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



WWW.COLOSTOMYUK.ORG

Contents



Colostomy UK

News	6
Rugby League	7
Trina Mant: From Isolation to Acceptance	18
Carers Week: Ellie and David	29
Fundraising Campaigns	36
	44



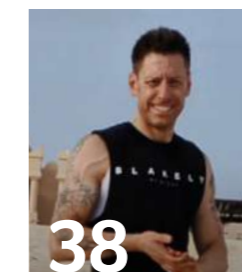
Real Lives

Izzy: Waking from a coma with a stoma	10
Amazing Jobs: Serving in the British Army	20
Mat Dean: Mind over Muscle	22
Lillie Dodd: The Superpowers of Miss Lillie and Her Mum Emma	31



Wellbeing

Jo's Diary	8
Dear Nurse	14
Blockages and Adhesions	34
Kev Harvey-Austen: Life with a Parastomal Hernia	38
Jackie Dudley: Managing a Hospital Stay with a Stoma	40



Support

Community and Support Group News	16
Your Letters and Emails	46
Support Group Listings	47



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

Get in touch
Order your free copies today

0118 939 1537
(10am-4pm, Mon-Fri)

hello@ColostomyUK.org

www.ColostomyUK.org/information

Support our work

Every guide, every call, every conversation we offer is only possible because of the generosity of our community.

Scan to donate or find out how you can support us.



charity number 1113471





news

Colostomy UK is a Winner of the 2026 GSK IMPACT Awards!



We are absolutely thrilled to announce that Colostomy UK has been selected as one of the winners of the GSK IMPACT Awards, 2026.

A partnership between the pharmaceutical company, GSK, and The King's Fund, this prestigious award is gifted to just ten small charities each year for their outstanding contributions to improving the UK's health and wellbeing.

The award is a huge honour, not least because of the intensely rigorous assessment process it entails. "IMPACT" is an acronym standing for Innovation, Management, Partnership, Achievement, Community focus, and Targeting need. Applicants must evidence how they are excelling in each of these categories.

Hundreds of promising candidates apply each year, and a forensic review of each organisation and its services awaits those which make it through to the final stages of evaluation.

That is why winning this award is so much more than the prize money and development opportunities it offers (as vital as these both are for a charity of our size) – it is a validation of all the hard work, care, and dedication that our volunteers and staff put into their roles 365 days a year. As the judging panel themselves noted:

"Colostomy UK stood out for its powerful lived experience leadership and the scale of its impact – both locally and nationally. The charity's work is both compassionate and influential, improving everyday life for thousands of people while shaping the future of stoma care in the UK. Its combination of peer-led support, policy leadership and stigma reducing campaigns demonstrates truly exceptional achievement."

Lisa Weaks, Senior Associate at The King's Fund

Given the Impact awards' reputation for excellence, our win also sends a positive signal to other donors that Colostomy UK is a strong, reliable partner which delivers on our promises to the communities we serve.

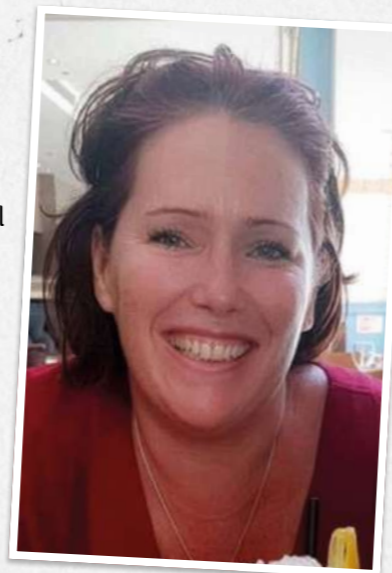
For instance, the award judges commended Colostomy UK for our bold and creative campaigns that challenge stigma and improve everyday life for people with a stoma. This includes our stoma-friendly toilet campaign, and newly launched Stoma Mythbusters initiative.

Judges were also impressed by our breadth of services, such as our freephone helpline, sexual wellbeing project, sports and wellness activities, literature titles befriending service, and of course, for Tidings magazine too.

We were also recognised for our national reach and strong partnerships. These include feeding into UK government initiatives, collaborations with businesses and the aviation industry, and university research projects, all with the aim of improving the lives of ostomates across the country.

As our CEO, Libby Herbert stated:

"Winning this award is a powerful endorsement of why we exist – to make a positive difference for anyone impacted by a stoma or stoma surgery."



Libby Herbert

FREephone STOMA HELPLINE: 0800 328 4257

Team Colostomy UK Rugby League Updates

Giovanni Cinque | Marketing & Campaigns Manager | GetInvolved@ColostomyUK.org



'The Purps' open 2026 season with cross Pennines weekend

Team Colostomy UK got the 2026 season underway in March with a busy opening weekend.



Wakefield – Stanley Rangers and GB Police

We started at Stanley Rangers in Wakefield, taking part in a triple header alongside the hosts and Great Britain Police. It was the first run out under new head coach Alan Bacon and captain Matt Turner.

The day also marked the return of Jordan Colbeck. Before his stoma surgery last summer, Jordan had played for both Stanley Rangers and GB Police, so it meant a lot for him to be back on the field, this time representing Team Colostomy UK.

He said beforehand:

"To have three teams that are close to my heart, that helped me both physically and mentally over the last few years will be something special.

I will also make my Team Colostomy UK debut that day which is something I've been looking forward to since my stoma surgery last summer."

There was a good feel around the day from the start. All three teams bought into it and it made for a positive environment.

On the pitch, it was a solid first hit out. Stanley Rangers were well organised, GB Police were physical, and for us it was about getting back together, getting minutes in and starting to build again after the off season.

Widnes Vikings

The following day, our wheelchair team travelled to Widnes Vikings and came away with a 70-18 win.



It was an outstanding result, especially given how the same fixture went last year, and a good way to start the season. While the focus is always on awareness and giving people the chance to play, there is a competitive element to this group as well and a real focus to learn and improve so the

result was a real statement for how we plan our approach this year.

Coming up!

There is plenty coming up over the summer and we would love people to get involved however they can.

In June we face Wakefield Trinity PDRL* in a curtain raiser to the Super League game between Wakefield and Hull Kingston Rovers.

After nine years, this will be the first time we have played as part of a top tier professional matchday, and one that is live on the BBC. It is a big step for the team!

It puts us in front of thousands of people on the day and many more through Wakefield's channels, which is exactly where we want to be.

That weekend is followed up on the Sunday with a wheelchair fixture against Wakefield, so it is a good opportunity to show both sides of the team across the same weekend.

Then, on August 23rd, we'll be represented by both our Wheelchair and Walking Rugby League teams when we participate in the York Knights inclusion day, part of their Super League game with Leeds Rhinos. Another really high-profile day for us, so come along and support us if you can!

If you'd like to find out how you can get involved as a spectator, player or volunteer, please email Giovanni at

GetInvolved@ColostomyUK.org



TIDINGS 82 | SUMMER 2026



Jo's Diary: Diving In

BY JO PRANCE

For the last two editions of the magazine, we've followed Tidings' Fitness Guru, Jo Prance, on her proctectomy journey (a procedure to remove the rectum). Having followed Jo's experiences both pre-surgery and immediately post-op, Jo uses her third and final instalment to tell us how things are six months on.

I am six months post proctectomy surgery and I am continuing to adjust to the changes in my body since having my rectum removed. Much has happened since my last article. I have undergone allergy patch testing following the post-operative reaction to the surgical glue, celebrated my 50th birthday, fulfilled my aim of getting back on the start blocks and competed in my first swimming race in over a year.

I have also re-booked to climb Kilimanjaro in July 2026, aiming to complete my charity fundraiser for Chameleon Buddies. This time my husband will be joining me on this adventure as we attempt to reach the summit together.

From the outside, it might look like everything has returned to normal and in many ways it has. I'm swimming several times a week, hiking in preparation for our Kilimanjaro trip, back to teaching, and even competing again. Completing my 1500m swim race at the end of March felt like a huge milestone, especially after navigating a few health-related setbacks. I'm proud of how much I've been able to get back into.

Of course, the journey isn't always straightforward and not everything is going swimmingly. Balancing physically demanding goals alongside ongoing health challenges can feel like a paradox, something I know many people can relate to. Yet, what stands out most is how much these experiences have strengthened my resilience and perspective.

Being in the water gives me an incredible sense of freedom, both physically and mentally. It's a space where I feel at ease in my body and no one is aware of the limitations and challenges I live with, for me it's the ultimate distraction and I feel normal.



When I'm training, I usually dive into the water, but in the lead-up to this competition I needed to check the fit of my race goggles, so I got out of the water to swap them over. My swimming lane was busy and diving wasn't an option, so without thinking I jumped in feet first. It was the first time I'd done that since returning to swimming, and it was a sharp reminder that my perineal scar is still there. The impact and rush of water smarted as the water rushed upwards carrying my swimsuit with it.

Most of the time I don't think about the scar anymore, which feels like real progress. This experience was a helpful reminder to be mindful in different situations, and although it was uncomfortable for a few days, it's something I can easily manage going forward. Next time it's busy, I'll simply ease myself into the water instead.

Another mistake was not ensuring my stoma bag was sat flat properly before pulling up my race suit. Swim race suits are incredibly tight and awkward to put on. In my eagerness to get into the suit, I failed to realise one of the edges of my stoma bag was sitting awkwardly. This only

became apparent once I started the race and I was aware of it digging into the top of my thigh. The discomfort I noticed during the swim, was soon overtaken by the sense of achievement and joy at finishing the race.

Since my surgery, my stoma, 'Anemone', has yet to return to its previously predictable daytime pattern and is still more active at night. This has meant dealing with increased wind overnight, which can disrupt my sleep. While there's no obvious reason for the change in my stoma's behaviour, I've been proactive in seeking advice from my stoma nurse and finding practical ways to manage it. Switching to a drainable bag at night has already made a positive difference in helping to release gas more comfortably.

I was advised that I could try irrigating my stoma but for now, as everything is functioning well, I'm choosing to be patient and give my body time to settle. Experience has taught me that recovery is rarely linear and often things improve with time.

Surgery is often undertaken to improve quality of life, and it can bring significant relief from difficult symptoms. At the same time, it's not without its challenges. Changes to the body can take time to adjust to, and sometimes new issues arise that require patience and ongoing management. It's a balance of gains

and adaptations and part of the journey is learning to navigate both, a situation I am very familiar with.

Proctectomy surgery has freed me from the mucus and rectal spasms I previously experienced, which has been a significant step forward. At the same time, the rectum plays an important role in supporting the surrounding pelvic structures, so its removal naturally changes the balance and positioning within the pelvis.

As a result, the pelvic floor muscles which support the bladder, bowel and other pelvic organs can also be affected. These structural changes may influence muscle coordination, strength, and sensation, sometimes leading to differences in bladder control, urgency, or a feeling of reduced support.

I'm learning to adapt to these anatomical changes which have impacted my bladder and pelvic floor function. For now, I'm managing these conservatively and focusing on what I can do to support my recovery, pelvic floor and wellbeing.



Whilst I recognise that my surgical journey may not be completely behind me, I'm very much focused on living fully in the present. I'm embracing opportunities to swim and compete where I can and continuing to celebrate this milestone year with more trips and experiences ahead. With our Kilimanjaro adventure now just three months away, I have plenty to look forward to and stay motivated for.



I woke up from a coma with a stoma – and found my life again

BY IZZY
Edited by Jillian Matthew



Izzy*, 40, from Buckinghamshire, describes how a traumatic experience changed her outlook on life and gave her a new focus and purpose.

Edited by Jillian Matthew

The person I was before my coma wouldn't recognise the life I live now

I woke up unable to move, unable to speak, and with no idea where I was or even what year it was. At that moment, I couldn't have imagined that this would become the starting point for a complete mental and physical transformation – a full reset on how I live, think, and see myself.

I was already in hospital when my colon perforated

I was admitted with bad stomach pains in late 2022. I had a CT scan which showed that my colon was inflamed, but the warning signs weren't picked up in time. What happened next is something I only know through other people because I don't remember it. Although I do remember the doctor's face who came to see me when I collapsed in the ward with unbearable burning pain in my abdomen. It turned out

my body was going into septic shock from my colon perforating and I needed emergency surgery. I was placed into an induced coma for 2 weeks while my body fought to recover from sepsis, which caused acute respiratory distress syndrome (ARDS) and organ failure. My lung capacity was down to 5%. My family were told multiple times that I would not make it through the night.

When I eventually regained consciousness, my body didn't feel like my own. I couldn't move or



communicate, and everything felt unfamiliar and frightening. I had damaged vocal cords from the tubes so couldn't speak for months. Initially I couldn't drink or swallow, and I couldn't lift my arms. I spent seven weeks in intensive care, slowly becoming aware of how much had changed. Eventually I was able to start moving. Once I was stable enough to begin rehabilitation, I underwent three months of physiotherapy. I had to relearn the basics most of us take for granted: walking, talking, eating, and drinking.

And alongside all of that came another reality – I now had a stoma

At first, it felt overwhelming. My body had changed, my independence had changed, and my confidence took a hit. Yes, I have a stoma bag. Yes, that means I have a disability.

But over time, I realised something important: it doesn't define who I am.

I didn't know what a stoma was and if I'd been told I needed one I would have said – no, I'd rather die than have it. But actually, it has changed my life. I no longer have the pains and sickness I had before. It turns out the nerves in my colon had not been working properly most of my life,

but it hadn't been picked up. The symptoms had always been put down to IBS. I had been in so much pain that I had to use Fentanyl patches, I was vomiting and couldn't eat properly.

Before all of this, I lived cautiously

I worried about what people thought, pushed through discomfort, and assumed there would always be time to do the things I wanted to do "later". Waking up in ICU stripped that mindset away. When you have to rebuild your body from nothing, you stop postponing life. You stop hiding. You stop letting fear decide what you can and can't do.



Recovery became about choice as much as healing. I joined a gym and slowly built my strength back up, step by step. I had lost so much weight from being in ICU, so it took around a year to fully regain my strength. I challenged myself physically, but also mentally – including pushing myself to go to a spa for the first time since surgery. I was very self-conscious about my stoma bag at first, but standing there surrounded by people, I had a realisation that changed everything: nobody is completely happy with their body. Everyone carries insecurities. Once I accepted that, I stopped shrinking myself and just got on with living.

Life didn't just return – it expanded

I have a loving partner who understands my circumstances, supports me fully, and also encourages me to push beyond my comfort zone. She's shown me that there truly is life after a stoma – and that stressing over the small stuff only limits what's possible. Before my surgery I was veterinary nurse. I am now studying for a law degree and want to go into family law, and I think I can really make a positive impact on other people's lives.

One of my biggest fears was flying with a stoma, especially long-haul travel. I was nervous about getting on a plane to visit my hometown in Cape Town, worried about my stoma, the bag, and how my body would cope during such a long flight. Twelve hours later, I arrived in the sunshine and had one of the best trips of my life. I trekked up a mountain, took a helicopter ride, went on safari, visited spas, and enjoyed plenty of African braais.

*Izzy' is a pseudonym chosen by the contributor



That trip wasn't just a holiday; it was proof that fear no longer gets to make my decisions.

Preparation turned out to be the key: I organised my supplies carefully, kept drinks to hand, and made sure

I didn't wait too long to use the toilet. Long haul flights are more comfortable than short haul, and the toilets are better.

I needn't have worried about going through the airport either, it all went smoothly. I wore a sunflower lanyard so staff would know I might need extra help or consideration. When I went through the body scanner it picked up my stoma bag, but the security staff just swabbed it and didn't make a big issue about it. I would say for anyone else travelling with a stoma for the first time to call the airline in advance and they will allow you to take extra luggage for your supplies. A few medicinal G&Ts can also help!

I've conquered some of my fears – not all of them – and that's okay

Every day still brings challenges, both for me and for my family. But mentally and physically, I am not the same person I was before. The shift has been total.

Initially I had a colostomy, but it wasn't working effectively, so two



years later I had further surgery and now have an ileostomy. I have found this more challenging. I don't have as much energy and must be careful what I eat to prevent blockages – a lot of fruit and vegetables don't agree with me anymore. I need to empty my ileostomy bag 6-8 times a day, compared to changing my colostomy bag once a day.

Which brings me on to one of the things that annoys me the most the lack of stoma-friendly toilets and people's attitudes to accessible toilets! I find there still isn't a lot of awareness about who might need to use them and why. You can find people using them with their kids, banging on the door telling you to hurry up because their child needs the loo or being left dirty, which isn't pleasant to use. One time a guy challenged me and asked me why I needed to cut the queue. I'm never quite sure how to react in these situations, but I just told him I had a stoma and asked him if he wanted to see my bag. That shut him up!

I genuinely believe I was brought back from my coma to live my best life

I now live with curiosity, confidence, and plenty of adventure along the way. That belief is what led me to start Pouch Pals, a support group for people aged 18-50 living with stomas. I was approached by a stoma nurse to start a group for people around my age. Often stoma surgery in younger people is done as an emergency. I didn't know about Colostomy UK when I had my surgery, and I had no one to turn to who understood what I was going through. If I can be there for even one person so they don't feel the same that's great. We're still to have the first meeting of the group and I have set up a website and Facebook page and group. Colostomy UK's Community Engagement Lead, Shauna Anne, is helping me get things set up.

It's going to be a space focused on acceptance, confidence, and moving forward – because life with a stoma isn't the end of the story. Because none of us should feel alone in this journey.

Because acceptance takes time. Because confidence grows when it's shared. And because life with a stoma doesn't have to be smaller — it can be bigger, braver, and more beautiful than we ever imagined.



CONFIDENCE COMES IN ALL SHAPES AND SIZES

Whether you are looking for a mini bag for holidays or a larger solution for travel or a hernia, Confidence BE® offers a range of options. Still the only bag to offer three different colour choices – black, white and stone – Confidence BE® allows you to match your bag to your outfit, underwear or mood.

MINI BAGS

Helping you feel confident in social or intimate situations: a discreet option for occasional use.



LARGE BAGS

Larger bag designs reduce the need for frequent emptying, supporting better comfort, rest and confidence, day and night.



LARGE 13-75MM WAFER

Our large, flat wafers can be cut to 75mm which offers greater stability on larger abdomens or around hernias.



SOFT CONVEX WAFER

If the stoma sits in a dip, is flush with the skin, or slightly retracted, our convex wafer supports the stoma to extend into the bag, improving flow and reducing leakage*.



CONFIDENCE BE® For all you want to be



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

Follow us
 @SaltsHealthcare:



dear nurse



Barbara Milleret
Clinical Services Lead Salts Healthcare

LIVING WELL: Supporting Mental Health with a Stoma

In mid-May, the UK marked Mental Health Awareness Week. Given the impact that life with a stoma can have on some people's emotional wellbeing, Barbara Milleret, offers guidance on managing mental health concerns from the perspective of a Stoma Care Nurse.

Living with a stoma changes more than how your body works. It can affect your routines, your relationships, how you feel about yourself, and your confidence. These emotional effects are completely normal. Whether your surgery was planned or emergency, whether your stoma is temporary or permanent, it's common to experience a mixture of relief, worry, frustration, and hope regarding your future. This article offers practical, kind strategies for supporting your mental wellbeing as someone living with a stoma.

While a person's mental health might be affected by having a stoma, this is only one side of the coin. Many people in the population may suffer from common mental health conditions, such as anxiety or

depression, for a variety of reasons. For those who also then require stoma surgery, their symptoms might be exacerbated. This article therefore also explores how having a stoma can affect the quality of life for ostomates diagnosed with such pre-existing conditions.

Whatever you're feeling is valid

There is no "right" way to feel after stoma surgery. People describe a wide range of emotions, often fluctuating from week to week as the body heals and routines settle.

If emotions feel like a rollercoaster, that is expected, especially during the first 3–6 months as you heal and you get used to products and routines. Early, honest conversations with your stoma care nurse can help normalise these experiences, troubleshoot practical issues, and reduce worry before it becomes a bigger issue.

Anxiety often centres on "what if" questions: What if I leak? What if there's odour? What if I can't find a toilet? What if people stare?

It's understandable. Your brain is trying to protect you from things that can go wrong. While we can't erase uncertainty, we can reduce it and build coping mechanisms.

Here are some common areas of concern followed by practical steps you can take to cope:

Common concerns:

- » **Leaks and odours.**
Early product trials can feel stressful as you determine the right accessories and stoma care routine for your individual needs.
- » **Travel and public transport.**
Worries about finding toilets or managing changes on the go.
- » **Work and social events.**
Meetings, long days, or unfamiliar venues can increase anxiety.
- » **Sleep.**
Fear of night time leaks can impact rest.



Practical tools that help:

- » **Routines that reduce guesswork.**
Set a routine that suits your output pattern (your nurse can help tailor this). Keep supplies in a consistent place and pre pack a "go to bag".
- » **The 'Rule of Two'.**
Carry two of each essential (pouch, wipes, disposal bag) when leaving home. This may help to lower your anxiety when out and about.
- » **Venue planning.**
When possible, check toilet locations before you go. Many venues list accessible facilities

online; maps can be saved to your phone.

- » **Journaling patterns.**
A brief log of meals, output, and activities can reveal patterns (e.g., certain foods before travel days, best change times). This can boost a sense of control.
- » **When anxiety sticks.**
If persistent worry limits daily life, ask your GP or stoma nurse about psychotherapeutic support. Therapies such as Cognitive Behavioural Therapy (CBT) can offer strategies that target health related anxiety effectively.

How your stoma care nurse can help

Specialist stoma nurses can often support with more than just your medical needs. They can provide holistic care which includes practical, emotional, and educational support to help you manage life with a stoma.

Skin care, diet, travel preparation, activity planning, trying different products, and making small adjustments to your accessories, are all part of the conversations you can have with your stoma care nurse, and which can help reduce depression, anxiety, and self-esteem issues. So don't feel you must wait for a crisis to reach out.

Consider asking for extra support if, for two weeks or more, you notice:

- » Persistent low mood or loss of interest in activities
- » Constant worry that feels hard to control
- » Avoiding leaving the house or seeing people
- » Significant changes in sleep or appetite
- » Thoughts of self-harm or feeling that life isn't worth living*

Talking to your stoma nurse can also help to normalise your experiences. You might be surprised to discover "many people feel this way at first." Hearing other people's stories may help.

Advocacy and signposting

If low mood or anxiety is persistent, your stoma care nurse may signpost you to your GP who is able to assess mood and anxiety. They can then signpost you to talking therapies or other types of interventional therapies, alongside reviewing any relevant medication that you may be on.

Your stoma care nurse may also be able to suggest other appropriate options to alleviate low mood and anxiety. For example, local peer support groups, or a direct referral to local mental health services.

Many stoma nurses may also refer you to Colostomy UK which runs a variety of initiatives, all staffed by volunteers with lived experience, aimed at improving mental health and wellbeing.**

*If you are experiencing any of these thoughts, contact your GP urgently or call Samaritans on 116 123.

**Colostomy UK's services include a free helpline, online chat function, wellbeing classes, befriending service, and support group guidance, all aimed up improving mental wellbeing.

Pre-Existing Mental Health Conditions and Stoma Care Support

According to Public Health England, one in five people in England are living with a common mental health condition such as anxiety or depression. For people who already live with a diagnosed mental health condition, adjusting to a stoma can bring an extra layer of complexity as it can magnify symptoms. This does not mean the journey will be harder for everyone, but it does mean that existing mental health needs deserve specific, proactive support.

People with a history of trauma, body dysmorphia, or disordered eating may experience a stronger emotional reaction to body changes. Medication routines may need review. Absorption changes (especially with high-output stomas), appetite changes, or disrupted sleep can occasionally impact psychiatric medication schedules also.

It's important to recognise that when you already have a lot on your mind, it can make keeping on top of your stoma care more difficult. If you are also managing your mental health, it's understandable that this can sometimes feel overwhelming.

If you have a history of mental health needs that are separate from your stoma care, but feel that your stoma may be making things more difficult, speak to your stoma care nurse. They can work with you to ensure you receive the right support and help you access additional services if needed.



Contact us at

hello@colostomyuk.org

or visit the Colostomy UK website for more information.





Community and Support Group News

Our Community Engagement Lead, Shauna Ann, shares all the news from stoma support groups across the country, as well as updating on all of Colostomy UK's latest community-based initiatives – read on for how you might be able to get involved yourself!

Bassetlaw Support Group summary

Best friends, Sarah Knowles and Sue McManus recently set up a new Stoma Support Group in Bassetlaw, Nottinghamshire. Sarah explains how it came about, as well as how their launch party went.

Sue and I met 3 years ago when she brought her dog Monty to my place of work for dog grooming, day care and training. Since then, we developed an inseparable bond where our common interests expanded much beyond dogs!

I've always been into hiking and walking, whereas Sue (then 70) hadn't walked much further than round town! She began to explore the trails with me and loved getting out walking. I introduced her to the Mighty Hikes for MacMillan where she has completed two 13 mile hikes. It was here I developed a keen interest in stoma care, ensuring her hydration levels were monitored along with food intake and how to physically manage her stoma while there were no facilities for miles around.

Sue had always wished there was a support group nearby, especially given that in the 8.5 years of having her ileostomy, she hadn't knowingly sat with anyone else with a stoma. Bassetlaw Stoma Social was founded as a social network for ostomates where likeminded individuals and their support crew could come together. We wanted to break down barriers and reduce isolation for ostomates living in Bassetlaw.

We had our launch event on 11th April with over 40 attendees. There were 18 ostomates and their support network. The event was supported by Coloplast UK, Salts Healthcare and had a video link with Colostomy UK to discover more about stoma friendly toilets.

We had the support of local businesses too. Fusion Energy Café offered their facilities for the event very generously (and have also provided the first stoma friendly toilet in Bassetlaw!) Absoluteness Counselling, who have worked with stoma patients around acceptance or diagnosis, and finally, Keep Moving Sports Massage & Fitness who did a chair exercise class to teach about movement in the body with a stoma.

The event was a roaring success! Future events will be held on the last Saturday of every month, at 11am, Fusion Energy Café, Worksop.

WAMS has a big bash!

WAMS (Windsor, Ascot, Maidenhead, Slough) celebrated their 7th anniversary in March. Our very own Campaigns and Marketing Manager, Giovanni Cinque, helped with the set up of the group way back in 2019. The group celebrated this milestone with a party complete with birthday cupcakes and a Super Stoma Quiz.



The Next Generation of Stoma Care Nurses?

In January, and again in March, Colostomy UK volunteer, Linda Griffiths, spoke to prospective first-year nurses about living with a stoma at the University of Chester.

The 100-strong crowd of students were very engaged and had some fantastic questions for Linda. From how the NHS is coping with stoma care given the pressure it is under, all the way through to personal questions on intimacy.

A number of the students spoke to Linda at the end of the session to thank her for the talk. One was so inspired that she is now considering specialising in stoma care!

Libby and Max with Ken Edwards and Michael Slater



Twenty Years On and Still Going Strong

In April, another Support Group also marked a major anniversary. Wessex Stoma Support Groups celebrated their 20th birthday. Our CEO, Libby Herbert, and Volunteers Manager, Max McGinley, joined the groups in recognising this incredible achievement. 40 attendees enjoyed presentations from local Stoma Care Nurses and MP John Glen, amongst others. Chairman Ken Edwards announced his upcoming retirement, with Brian set to succeed him. The very engaging afternoon ended with a lively sing-along and raffle.

An Open Day in Milton Keynes

Colostomy UK's very own Peta Barratt attended an Open Day for Milton Keynes Stoma Support Group.

Peta manned the charity's stall and did a great job of speaking to guests about our products and services. A number of people showed an interest in volunteering for Colostomy UK so watch this space!



Peta in action at the Open Day

Community News

Badge of Honour

In our last Community News update, we briefly mentioned how our Stoma Care Workshop was recently given CPD Accreditation. We felt it was only right to share a little more about what this means in practice as it is a huge achievement for our small but mighty team.

The course has been independently checked and approved by the Continuing Professional Development (CPD) accreditation body. This is important to us, as it shows the course content is of a very high standard and meets regulatory requirements. In short - it's a big badge of approval from the assessing authority.

So what does the Stoma Care Workshop include, some of you may ask. The workshop offers guidance to people in caring roles, whether they are unpaid family members, or professional carers, to best support ostomates with their stoma care needs.

The course is available to health and social care professionals to book as a group at a charge ranging from £20 - 40 per person.

People who provide unpaid care and support in the home can access the course for free on the following dates:

- » June 16th 18:00 - 19:30
- » October 13th 13:00 - 14:30

For smaller organisations, there is the option to book individual employees onto the workshop on the following dates:

- » May 22nd at 2pm
- » September 11th at 2pm

If you are interested, please contact us at:

getinvolved@colostomyuk.org

A Research Opportunity for Our Readers

The Fistula Research team at St Mark's Hospital is developing a sexual function questionnaire to support people after non-cancer colorectal surgery, including stoma formation.

The team is looking for volunteers to take part in a short (30 minute), confidential online interview to give feedback on the draft questionnaire. Your input will help make sure it's clear, relevant and useful for patients.

If you are interested in participating, please contact Shivani Joshi at:
lnwh-tr.sexprom@nhs.net.

SHARE

Got something you'd like to share?

If you'd like to highlight the great work of your Support Group, why not get in touch with us and tell us all about it.

We would also love to hear from you if there have been any changes to your support group. For example, if the group has had to close, changed its regular meeting slot, or its primary point of contact.

Whatever you'd like to share, you can reach us at:

getinvolved@colostomyuk.org

Trina



FROM ISOLATION TO COMMUNITY:

Trina's Journey Towards Self-Acceptance

Between the 15th and 21st June, the UK will recognise National Loneliness Awareness Week. Loneliness can take many forms. A person can be surrounded by people yet still feel isolated and alone, because those around them are unable to relate to what they've been through. It's an experience many people living with a stoma report feeling, which is exactly why Colostomy UK offers a Telephone Befriending Service.

Here, we tell the story of Trina Mant, who generously shared her experience of using our Befriending Service, highlighting the positive impact this has had on her life.

Please note, this story contains mention of suicide.

Trina Mant, a former Healthcare Support Worker, underwent an elective colostomy in June 2024 due to deteriorating health. The surgery marked the beginning of a deeply challenging period in her life - not because of the physical change, but because of the prejudice and stigma she faced at the time.

Trina experienced rejection and hurtful comments from some friends and family members. It seems many of those close to her struggled to

understand her decision to opt for life with a stoma. As one family member noted:

"Who in their right mind would choose to have a bag hanging from their stomach?"

Feeling isolated, depressed, and misunderstood, Trina's mental health declined significantly. She experienced severe anxiety and depression and made two suicide attempts by overdose.

Reaching Out for Help

Trina's local Stoma Care Nurse suggested she contact Colostomy UK. Trina subscribed to Tidings magazine, which she describes as a turning point. The magazine encouraged her to get in touch with Jo McKenzie at Colostomy UK, who recommended the befriending service.

Trina was matched with Suzanne, a befriender with lived experience and who could genuinely relate to her challenges. From the very first call, Trina felt understood for the first time. The pair spoke every month for 30 to 60 minutes, and Trina credits Suzanne for helping her see that she was not alone, and that there are people who truly care and understand.

Accessing Community Support

Suzanne encouraged Trina to join the Mercia Stoma Support Group, even though it was over 30 miles away. Despite the distance, she now attends regularly and rates the group as 10 out of 10. She says the group

has been "life-changing", providing both emotional understanding and practical advice.

Through the group, Trina also found a specialist dermatologist at York Hospital, who is now investigating her severe skin issues around her stoma. Suzanne also helped Trina explore irrigation and arranged for resources to be sent via Colostomy UK.

How Befriending and Support Groups Have Helped

With time, support and encouragement, Trina has moved from despair to acceptance - and even pride. Trina's self-confidence has grown considerably. She ignores the judgement of others and instead chooses to focus on her wellbeing. As she explained:

"I am content with myself and my stoma, I am more upbeat and have my old spark back. I'm heavily involved in my new [stoma] community and no longer withdrawn and ashamed. Suzanne has played a massive part in this transition and I'm now looking into becoming a Befriender myself"

For more information on Colostomy UK's Befriending service, call: 0800 328 4257

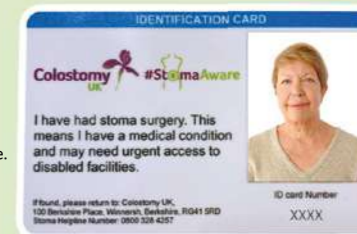
***If you are struggling, please contact Samaritans on 116 123**

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

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

A Colostomy UK Photo ID card, can be helpful if you need to use accessible facilities urgently, particularly if they aren't part of the National Key Scheme.

You will need to include a copy of your prescription or delivery note as proof of eligibility, and if ordering an ID card please also include a passport-sized photo.



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

Title: _____ Address: _____
 Name: _____
 Tel: _____
 Email: _____ Postcode: _____

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

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

Please tick as appropriate:

- I would like to receive a Radar Key for £5 - set of 2 keys (inc. postage and packaging)
- I would like to receive a photo ID card for £6.50 (inc. postage and packaging) and enclose a passport photograph.

Return all required items to: Colostomy UK, 100 Berkshire Place, Winnersh, RG41 5RD. Cheques should be made payable to Colostomy UK.

For payment by credit card, send your documents in the post with a contact telephone number, we will then call you to take a card payment when received. (If you have any queries or would like to pay by credit card, please contact Colostomy UK office: 0118 939 1537 or hello@ColostomyUK.org).



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

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

For more information visit:
www.ColostomyUK.org/gift-aid
 or email GetInvolved@ColostomyUK.org

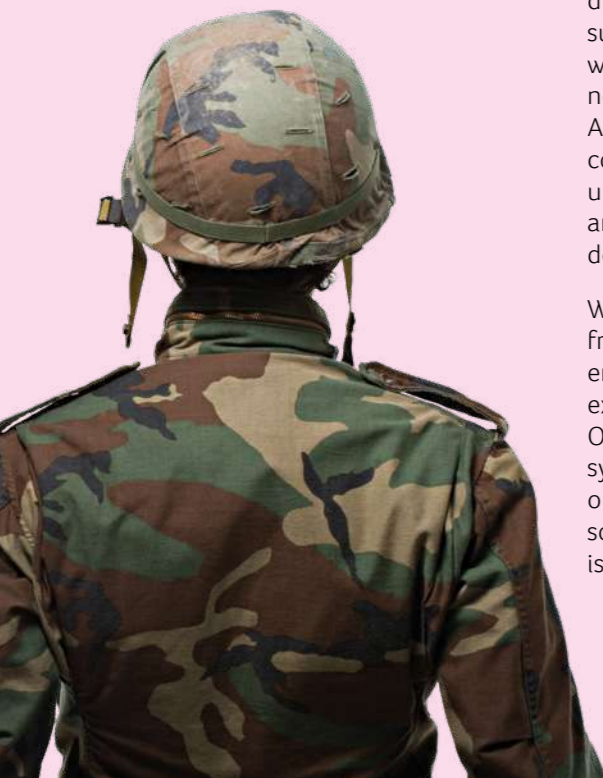
giftaid it





**UNIQUE AND EXCITING JOBS:
Serving in the British Army**

In this new series, we explore the unique, exciting, and outright unusual jobs which many ostomates hold, proving that life with a stoma needn't be a barrier to a fascinating career. We start with a member of the British Army currently serving overseas*.



Life with a Stoma in the Armed Forces

I had my stoma formed in 2014 after surgery for cancer. Medically, I have been fortunate so far, as most of my bowel is relatively undamaged, and I have fewer concerns and risk of complications than others I have met in various support groups or read about in Tidings.

While the Army was great both in supporting me during treatment and in the recovery period afterwards, I had many months when I thought I would be discharged as no longer medically suitable to serve. I also thought I would choose to leave, as I could not really imagine staying in the Army with a stoma. That was a real concern as I had effectively joined up from school, was otherwise fit and active, and could not imagine doing anything different.

With hindsight I have really benefited from being in the military. It is a large employer with lots of medical expertise and a well-developed Occupational Health team. The system was fairly well set up to work out what is and is not possible for someone in my position, and what is best for both me and the Army.

Those in command are used to managing people in periods of recovery or long-term sickness, and you are assigned into roles within the limits of your medical grading. Most people I work with know absolutely nothing about my stoma unless I say something.

I won't pretend that it has always been straightforward or always positive, but mostly good. The worst was when concern about my colostomy caused the last-minute cancellation of my assignment to a new location when my house and family were already packed up and ready to move. But looking back, this actually meant I was then available for a different job, which turned into a good opportunity and created a new sequence of jobs and moves around the UK and overseas that has been great for me and the family.

There has been quite a change in the world since I first joined up. From the overseas campaigns in Iraq and Afghanistan to today, with more of a focus back on Europe and the threat from Russia.

Naturally my role has changed since my operation, but I was getting older and more senior and so would have been doing more office work anyway.

Tough Training for an Ostomate

I have been doing this for over 25 years now, the last eleven with my colostomy. My role in the Army remains fairly varied, even if in later postings I have become more of an office worker in headquarters.

Even so, we are all required to remain fit and active and complete mandatory training activities every year. I was also an instructor in outdoor skills from before my surgery and that has continued and brought me great happiness.

There is something about being out in the wilds of Scotland or Scandinavia, relying on a map and compass, and being able to pass on real experiences to those just starting out.

Navigating Stoma Supplies and Support While Serving Overseas

As an ostomate moving around the UK and then living at bases overseas, most of the challenges are with administration rather than medical.



While my GP is on the base or in a garrison town, the military pharmacy may not have any experience in getting stoma supplies. This has created the sorts of dramas that are sadly too common - missing items and strange substitutions. Though I have also had the reverse experience. For example, once when I was moving on to a new location, colleagues had taken the initiative to get me in a healthy emergency stock of supplies, which they insisted I take to make the transition period easier.

Now stationed overseas, I use a local supply company. While many brands are multinational and Google Translate helps on websites, I have discovered that (just as in the UK), some areas permit certain items and yet seemingly without reason, not others. Currently I am in a country where support belts will only be provided once you actually have a hernia!

In the UK, I always tried to get a referral to be on the books of the local stoma nurse team, which my military GP could arrange. Even if I never went in and saw them, I wanted the reassurance of another phone number and the ability to call an expert if things went strange or really wrong. I also had some great help and learned a lot in the early days from local support groups. Though it was hard to fit in with work, it was always worth it.

On Expedition

I know it is not suitable for everyone, but irrigating gives me a huge amount of freedom and enables 90% of what I could do before my operation with little change. When heading off into the mountains to teach young soldiers map reading and other skills, I can often go 48 hours without any concerns, and it makes wearing a rucksack and other things on my waist much more comfortable.

Like most ostomates, I do not like having all my eggs in one basket, so a colleague will usually also carry some spare supplies for me. It is at these moments, (departing on isolated training exercises with a new group) that I usually just come out and explain. I used to wonder what people thought, especially those in their late teens or early twenties. But I have often heard back something like "my nan had one" - and you realise how many families have been touched by stomas, and how great most people are.



***Name and photo withheld due to security requirements relating to the publication of personal details of those serving in HM Forces.**

Opinions expressed are personal and are not to be taken to represent the views of the Ministry of Defence or the British Army.



Mind Over Muscle

As a bodybuilder, Mat Dean was used to putting his body to the test. But nothing prepared him for the onslaught of health issues he has endured over the past several years. Physical fitness definitely helped, but a strong mental attitude was arguably his greatest secret weapon.



“From about the age of 20, as a smaller-framed guy, I always wanted to be bigger and better myself”

Mat Dean tells me early on in our video call. Even though he is sitting in his car throughout our conversation, it is easy to see he has achieved this goal. Now 42 years old, Mat has dedicated much of the past 20 years to either weight-lifting or bodybuilding competitions. Stacked, broad shouldered, and sporting a large, thick beard, Mat is the type of guy at the gym who could easily intimidate those of us still inhabiting our (albeit older and somewhat less taut) 20-year-old frames.

But Mat’s towering physique belies the fact that he is, in reality, a gentle giant. A doting father and a committed partner to his fiancée, Holly, it is clear that he has found a lot of emotional strength through the support of loved ones. And he’s needed it, because Mat’s imposing build also belies the long, complicated, and often very scary journey he’s been on with his health.

Over the past several years, Mat has contended with a staggering and unenviable array of conditions and treatments. His commitment to exercise has allowed him to bounce back quickly each time something hit, yet it was also his intense fitness

regime that first raised alarm bells around the real state of his health back in 2021.

At the time, Mat had not long retired from his first sporting love of weight-lifting – a gruelling pursuit which, as the name suggests, sees competitors pushing, pulling and carrying colossal weights: “I lifted weights I never thought were possible” Mat reminisced. This included once winning a competition by lifting 300 kilos (roughly 48 stone) from the floor. One of his proudest moments, he explained.

But the toll this sport has on the body is by no means insignificant, and with

a physically demanding day job as a landscape gardener, Mat switched to bodybuilding instead. A key difference being that, while weightlifting requires competitors to bulk-up, bodybuilding is quite the opposite, as Mat told me:

“With bodybuilding, it’s all about exposing lean tissue with zero fat. You strip away all the rubbish that you don’t need. Working with a coach, I went from 18 stone doing power-lifting down to 12 stone doing the bodybuilding. It was probably the best shape I’d ever been in.”



Then, seemingly out of nowhere, Mat was struck with pneumonia. Was it caused by the sudden shift in training and diet I wondered?

“It’s a hard one to gauge. When you’re getting close to the competition, you’re running on very little food. Your energy levels are low. So the body is probably at its weakest. I asked the doctors, and they couldn’t say either way though. Could just be one of them things”.

Regardless, the dramatic turn of events saw Mat pull out of the competition. His coach recommended he rest and be kind to himself. Mat took this as a green light to drop the intense diet he’d been on while preparing for the show – but this was not without its consequences:

“I just ate like a pig for the next three days – pizzas, pasties, cakes, chocolate, sweets, all the things I hadn’t had for months on end, and my weight skyrocketed from 12 to 15 stone in four days”.

Mat’s bowel also went into overdrive. He found himself constantly running to the toilet with loose stools. He was also passing blood and had pain in the left-hand side of his stomach. Perhaps understandably, he put this all down to the bowel being shocked by the dramatic change in diet. Mat’s GP also examined him but found nothing ominous, so broadly agreed with his theory.

Soon however, his body and bowel stabilised, and life continued as normal, until he and his coach began training for the next bodybuilding competition. Once again, his bowel quickly made sure Mat knew it wasn’t happy with the intense shift in diet. Yet as unpleasant as it was, he was able to rationalise it.

“You deplete yourself right down to the point where there’s very little glycogen in the muscle, then you put a lot of carbohydrates in the system days before the competition, which inflates the muscles out, tightens the skin, and gives you that cartoon of bodybuilding look. As we started doing that my bowels flared up. I was rushing to the toilet almost uncontrollably”.

It was just sheer luck that on the day itself, Mat’s bowels behaved, and he was able to compete, coming second in what was his first ever bodybuilding show. Life went on. Mat’s partner Holly gave birth to their daughter, Willow, and the family went on holiday with Mat’s older children. But Mat continued to experience intermittent bowel issues.

Another visit to the GP and closer inspections at hospital finally

confirmed that he had a golf-ball sized tumour in his colon, which had been growing for two years and had now metastasized to his liver. Had he expected this result?



“No! It was a shock for me and Holly. I was fit as a fiddle. The week leading up to the actual scan, I’d wheelbarrowed 16 tons of stone up a garden in my day job.”

Mat was 39 years old, with a fiancée and five children, including six-month-old Willow.

“It was obviously a concern, you know, of what happens next” Mat recalled.

‘What happens next’, a consultant explained, would be surgery to ease pressure on the bowel and to form a stoma. For someone who strives for bodily perfection, this news was hard to hear.

“I’d heard of a ‘colostomy bag’, but never of ‘stomas’. I’d never seen one, I didn’t know how they worked, or anything”.

Mat had little time to get his head around things, however. Before his planned surgery could go ahead, he fell seriously ill. It was discovered that his tumour was growing so aggressively that it had now perforated his bowel and grown into his bladder. Emergency surgery was performed to ease the pressure on the tumour, and Mat woke to see his new colostomy for the first time, as he explained:



“To be honest, it upset me. Being into bodybuilding and being quite body conscious, having something visually changing how I looked with my top off was quite a hard pill to swallow. The idea of scars bothered me enough when I first got told I was gonna have my stomach cut open. But then to have a bag stuck on me that contained my waste was a lot to mentally process.”



But life with a colostomy was only one thing Mat had to contend with at this time. He was still living with the tumour itself. Owing to its size, he'd first need a course of chemotherapy to shrink it so as to remove it safely. But before this could begin, Mat was struck by a major infection which doctors struggled to get under control. Steroids, antibiotics, and even a PICC line to the heart were all attempted to alleviate the symptoms, but eventually it was decided further surgery was essential to save him.

Doctors explained to Mat that there was a chance this might mean losing his bladder and a second stoma formed as a result. But he also understood he had little real choice in the matter. “Just take the flipping thing out” he'd told them, “It's trying to kill me”.

Sure enough, when Mat came round from the surgery, he discovered that alongside his colostomy, he now also had a urostomy. If the former had been difficult to accept, then the latter was a whole other level.

“It's not just losing my bladder - it affected every part of manhood. You don't wee. You struggle to get erections. You can't have kids. It's a massive thing.”

Mat scarcely had time to process the enormity of everything that was happening to him however, as soon after this, he had to contend with the course of chemotherapy which had

been on hold. Sadly, the chemotherapy failed to shrink the tumour, meaning Mat faced a third major surgery to remove what was also now an affected portion of his liver. Thankfully, the operation was a success and Mat again recovered well owing to his robust fitness levels.

Even at this point, Mat was by no means out of the woods, however. Over the coming months he would suffer a twisted bowel not once but twice, requiring yet more emergency surgery when he had just 24 hours to live.



Fast forward some months, and Mat found himself battling yet another health crisis. A Urinary Tract Infection (UTI) had gone undetected long enough to reach his kidneys, putting them at critical risk of failure. UTIs are a perennial concern for urostomates, as the stoma makes it easier for bacteria to enter the system, while the usual telltale signs of infection are harder to detect, meaning problems can escalate quickly. For several days, Mat's condition remained precarious, until antibiotics finally gained the upper hand.

Then, in January 2025, Mat finally underwent what he hopes will be his last ever major surgery, this time to reverse his colostomy. However, while the operation was a success, he was left needing to go to the toilet between 30 – 35 times a day in the weeks following the procedure. It was another incredibly challenging time. Despite how debilitating his daily routine was, Mat was now more determined than ever to get back to a normal life - which for him meant back to peak physical fitness:

“One of my best mates was having his Stag Do in Ibiza in the May. This was the kick up my ass I needed. I wanted to be in good shape for it. But it was a challenge, because of how often I was needing the loo. I even moved the treadmill outside the toilet door to make things easier.”

Not only did Mat manage to get his athletic form back ahead of the holiday, but the routine was also a turning point for him psychologically:

“It did wonders for my mental health” he explained, adding “I proved to myself I could still do these things”.

Any further training for bodybuilding competitions was in serious doubt, however, given that all the medical advice he received after having his stomas formed warned him to avoid lifting heavy weights or any strain on the abdomen due to the risk of hernias. It was advice Mat heeded while recovering, but as time passed, he was left wondering what the rest of life would be like if he would never again get back to his preferred size and strength. Not only would he be unable to return to his beloved bodybuilding, but he was at risk of losing his entire livelihood as a landscape gardener too.

As he explained:



Mat with son Ethan and Fiancée, Holly

“I work with my hands. Come rain, shine, or snow, it's what I enjoy doing and it's all I know.”

Mat began to question whether the advice he'd been given, which was of course tailored to the general public, failed to account for his own unique experience as an avid gymgoer. Cautiously, he began reintroducing weights into his exercise routine, under careful supervision from his coach. Thankfully, Mat's diligent planning worked. Over time he returned to lifting heavy weights and working outside once again.*

Now Mat had just one final goal in sight - to compete in bodybuilding competitions once again. But it was one thing to be physically in shape again, and quite another to be psychologically prepared to return to the stage:

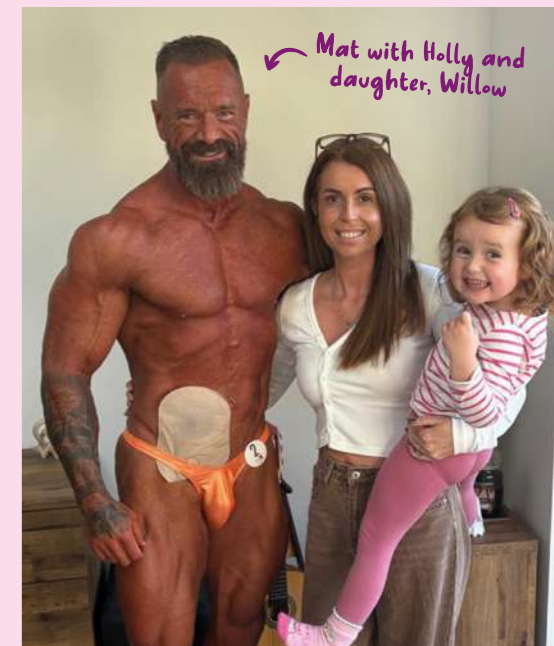
“I always wanted to do another show. I just didn't know if mentally I could process standing up there with the scars or with the [urostomy] bag.”

But encouraged by friends at his gym, Mat stepped outside his comfort zone and signed up for a competition. It turned out to be another powerful turning point on his journey:

“It was incredible. I thought I'd struggle with the fact I had the bag on show, but it was like it was invisible. It didn't matter. It was a part of me. Yes, other people could see it, but it just didn't faze me. And I thought then 'if I can expose myself mentally and physically like this, then I've got nothing to worry about'. It did me wonders and that's the way I now move forward.”

Buoyed by the experience, Mat went on to compete in the British finals, where he was placed 1st and 2nd in two categories. The things that Mat has achieved with his physical strength are undeniably impressive. Few people reach the levels of athleticism he has - and to do so in spite of all the medical complications he has endured in recent years is extraordinary. Yet it is arguably Mat's scars and stoma - both once a source of shame - which reveal his greatest strength is in fact his mind over muscle.

*Not many of us are built like Mat Dean! You should always seek advice from your stoma care team before attempting any exercise, particularly involving the abdomen.



Mat with Holly and daughter, Willow



“I will have a stoma for the rest of my life. There are good days and bad days of course, but anything I can do to feel more confident and really take part in life is so important to me. Having a bag I completely trust makes me feel more confident in myself. It truly means the world and makes all the difference.”

Natalie

NovaLife TRE™ Black Pouch

More Choice,
More Confidence.¹



Dansac TRE™ technology products have received official dermatological accreditation from the Skin Health Alliance, which may bring confidence and reassurance to those who use our products.



Scan to discover more

Request your sample today and see the benefits for yourself, visit www.dansac.co.uk

¹. Data on File, 2022: ref-04110 (n=30), 2024 ref-04111 (n=200)

Natalie is a Dansac product user who has been compensated for this article. The testimonials, statements and opinions presented are applicable to the person depicted. These testimonials are representative of that person's experiences, but the exact results and experience will be unique and individual to each person. The information provided herein is not medical advice and is not intended to substitute for the advice of your personal physician or other healthcare provider. This information should not be used to seek help in a medical emergency. If you experience a medical emergency, seek medical treatment in person immediately.

Prior to use, be sure to read the Instructions for Use for information regarding Intended Use, Contraindications, Warnings, Precautions, and Instructions.

All other trademarks and copyrights are the property of their respective owner. Dansac, the Dansac logo, NovaLife TRE and TRE are trademarks of Dansac A/S. © 2025 Dansac A/S. Expiry 2030.



Be the reason no one faces stoma surgery alone.


Will you donate to Colostomy UK today?

With your support, we're there for anyone undergoing stoma surgery – whenever they need us.

Thank you



Visit colostomyuk.org/donate Or scan the QR code 

Call us on 0118 939 1537 to make a donation over the phone 



Please support Colostomy UK

Every 39 minutes someone in the UK has stoma surgery

Your donation today, or pledge of a regular gift, will help ensure we can be there for every one of them. You can make a real difference in real lives.

SCAN HERE TO DONATE



Please complete and return this form to: **Colostomy UK, 100 Berkshire Place, Winnersh, Wokingham, Berkshire RG41 5RD.** Call: **0118 939 1537** to donate by phone or if you have any queries.

Bank details for donations: Colostomy UK, account number 88781909, sort code 60-17-21. Please add reference T82. Thank you



My Details (Please complete in BLOCK CAPITALS)

Title: _____ First name: _____ Last name: _____
 Address: _____
 Postcode: _____ Phone Number: _____
 Email: _____

I would like to make a one-off donation

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

£30 £50 £75 Other (please specify) £ _____
 I enclose a cheque or postal order made payable to **Colostomy UK**
 Please debit my Visa/Mastercard/Maestro Card with the amount specified

Card number _____ (Maestro only)
 Expiry date _____ Security code _____ (Maestro only) Start date _____ Issue No. _____ (Maestro only)
 Signed _____ Date

D	D	M	M	Y	Y
---	---	---	---	---	---

I would like to make a regular gift

I would like to make a regular donation of £ _____
 Monthly Quarterly Half Yearly
 Annually Commencing
 01 / _____ / _____ % 15 / _____ / _____

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

شكركم على هبتكم! Thank you for your gift T82

Thanks to the Gift Aid scheme – we can reclaim 25p for every £1 you donate to us from HMRC if you are a UK tax payer. All you need to do is tick, sign and date this declaration if you are eligible.

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: ____ / ____ / 2026

The Direct Debit Guarantee

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

This guarantee should be detached and retained by the Payer

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

Charity name: Colostomy UK

Name and full postal address of your Bank or Building Society

To: The Manager

Bank/Building society: _____

Address: _____

 _____ Postcode: _____

Name(s): _____

Bank/Building Society account number _____ Branch Sort Code _____

Service User Number

6	9	1	2	1	3
---	---	---	---	---	---

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

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

Signature(s) _____ Date

D	D	M	M	Y	Y
---	---	---	---	---	---



Celebrating National Carers Week: Ellie and David

With National Carer's Week set to take place between the 8th – 14th of June, we asked Ellie Wilkes to tell us about her caring responsibilities for her beloved grandad, David Sims.*

Tell us a little bit about yourselves:

My name is Ellie Wilkes and I am 26 years old, from Essex. I help care for my grandad, David Sims, who is 84 years old, a born and bred East End Chap, who's lived in Stratford his whole life.

Why did David have a stoma formed?

My grandad was first diagnosed with prostate cancer in 2000. It was a very difficult time for him and our family, but over the years he has shown incredible strength and resilience. For more than 25 years he has lived with prostate cancer, managing the condition with ongoing hormone treatment and regular medical care.

During one of his routine check-ups for his prostate, doctors recommended that Grandad undergo a nuclear medicine scan. This involved swallowing a special radioactive tracer, followed by a full-body scan using advanced imaging equipment to detect any abnormalities.

Sadly, in March 2025 grandad was diagnosed with colon cancer (doctors also discovered a lump on his lung, which has since been confirmed as lung cancer.) It was a devastating diagnosis for him and for all of us as a family. At the time, doctors explained that without surgery his life expectancy could be as little as one to two years.

In September 2025, Grandad was admitted to hospital for surgery to remove the colon cancer. Before the operation, doctors carried out a colonoscopy to understand exactly how far the cancer had spread. Unfortunately, the results showed that the cancer had progressed more than expected and because of this, the surgeons had to make a very serious but life-saving decision during the operation. The only way to



remove the cancer and give Grandad a chance of survival was to remove his entire lower bowel. This meant that he would need a permanent ileostomy. Although this was a huge life change for him, the surgery was necessary to save him. Doctors told us that without this operation he may not have survived until Christmas.

After the surgery, Grandad spent three days in intensive care while doctors and nurses closely monitored his recovery. It was a very worrying time, but thankfully he gradually became stable and was later moved to a general ward to continue recovering.



How has David adjusted to life with a stoma?

When my grandad was first diagnosed with colon cancer, he was very open about how he felt. One of his biggest concerns was the possibility of needing a stoma, something he made clear he desperately wanted to avoid. His feelings were completely understandable, as it's such a significant and life-changing adjustment for anyone to face.

Adjusting to life with a stoma has been a big change for him, both physically and emotionally. At first it was overwhelming, but with support from stoma care nurses he slowly began to understand how to manage it and adapt to his new routine. They helped explain how the stoma works, how to care for it properly, and how he can continue living his life with confidence.

*This article was written by Ellie, but David contributed throughout the process

**See page 16 for upcoming dates for our free course aimed at unpaid carers



Seeing him so worried and upset was incredibly hard for me. It was heartbreaking to watch him struggle with fear and uncertainty about what lay ahead. The idea of such a major change felt overwhelming for him, and as his granddaughter, it was deeply emotional to see someone I had always known as strong and resilient feeling so vulnerable.

Although the journey has been incredibly challenging, the surgery ultimately saved his life. As a family we are very grateful that he was given the chance to keep fighting and to continue spending time with us.

What stoma care support do you help David with as part of your caring role?

Grandad is largely self-sufficient, and as his granddaughter, my role is mainly to support him with practical tasks. I help by ordering his supplies - making sure he always has enough bags, wipes, and sprays - and by keeping track of his appointments with the local stoma nurse.

When and how did you both decide to step into a carer arrangement?

This was a natural agreement from last September. I just stepped in when my grandad needed me most.

Ellie, what is the best thing about being a carer?

Spending time with my Grandad. We have always been close.

David, what is the best thing about Ellie's support?

[David]: Ellie has been amazing from the day of my operation right up to today. She asked all the right questions, made me feel comfortable, and supported me every step of the way. I will always be grateful for everything she has done for me.

Ellie, is there anything you find challenging about your role?

Before my grandad's operation, I had no idea what a stoma was (no-one in my family did). I spent a lot of time researching so I could better support him and make sure he didn't feel alone. During that process, I came across Colostomy UK on Instagram and joined an online session covering the basics of stoma care. It was really helpful in building my understanding and confidence.**

In terms of my role, one of the main challenges can be supporting grandad emotionally when he's feeling low or frustrated, especially when there isn't an easy way to fix how he's feeling. It can be hard seeing someone you love struggle, but I try to be there for him, reassure him, and help him feel as comfortable and confident as possible in his day-to-day life.

Is there anything about being cared for that David says he finds difficult?

In the first few weeks after grandad came home from his operation, his stoma kept leaking, and he developed a rash around the area. We later discovered he was allergic to the original bags he had been given. This really affected him, as he became anxious about going out in case of leaks. Now that we've found the right bags and size for him, he's much more comfortable and managing well.

And we hear that you and David have very good news to end on....

Yes! On 13th January 2026, grandad was placed into remission for five years. Having the stoma has saved his life, and we will always be incredibly grateful for the second chance it has given him.

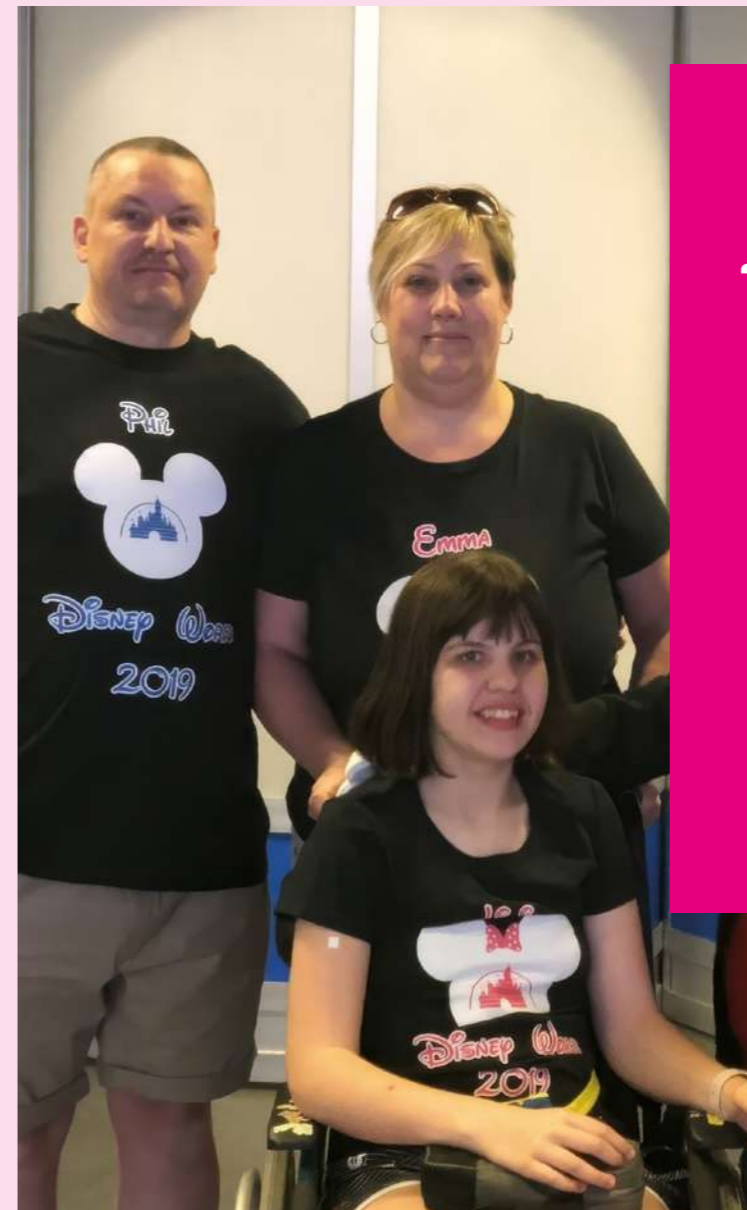
LILLIE DODD AND
HER MUM EMMA

The Superpowers of Miss Lillie and Her Mum Emma

WORDS BY
LESLIE MELLO



How Lillie Dodd and her mum Emma face rare disease, double stomas, and daily care with humour, grit, and a smile that inspires thousands.



Every superhero has an origin story

Lillie Dodd loves superheroes, and her favourite is Spider-Man. It makes sense. Like Lillie, Spider-Man is funny, brave, and quietly determined, even when things get hard. And he didn't get his powers because life was easy. He got them after something unexpected changed everything.

Lillie's "origin story" began before she was even born. She has a genetic anomaly — a duplication on chromosome 19 — so rare that she is the only person in the UK registered with it. Her condition doesn't even have a name. Instead, it's written as a

long line of letters and numbers: 19q12,30,765,107-31,823,229x3. It means little to most of us, but it shapes every part of Lillie's life.

Chromosome 19 plays a key role in smooth muscle function, particularly in the bowel and bladder. Alongside this rare duplication, Lillie also lives with type 1 diabetes, autism, learning disabilities, speech delay and anxiety. Together, these conditions require constant management and specialist care.

Emma, Lillie's mum and full-time carer, has her own superhero backstory. She cares not only for Lillie, but also for her husband Phil,

who has a degenerative spinal condition. Her days are filled with hospital appointments, medication routines, alarms, forms and phone calls — the kind of vigilance that can make every week feel relentless.

Ask Emma what her superpower is and she'll say it's persistence.

"The ones who speak loudest and most often get heard."



↪ Hannah, Lillie & Emma



Dave
Wendy

She has learned to chase appointments, follow up test results and question delays — because if she doesn't, things get missed. Tests don't happen. Appointments drift, and support slips through the cracks. Incredibly, she remains polite throughout, something anyone who has navigated the healthcare system will recognise requires superhero strength.

When people say, "I don't know how you do it," Emma answers simply:

"I do it because I don't have a choice."

She doesn't see herself as heroic. She gently challenges the idea that coping is a virtue, pointing out that it masks exhaustion and the weight of navigating systems that make caring far harder than it needs to be. She uses superhero strength daily — but in a better system, she wouldn't have to.

Meet the stomas: Dave and Wendy

When I first met Lillie and Emma over Zoom, I shared my own stoma story — waking up after emergency surgery to find a bag I hadn't expected, and how reading others' experiences helped me feel less alone. Lillie listened carefully, then shared joyfully:

"My stomas are called Dave and Wendy!"

Lillie has two stomas. Her colostomy is Dave. Her urostomy is Wendy — or,

as she cheerfully calls her, "Wee Wendy."

When I asked whether naming stomas was important, Lillie said yes, "because it's fun." Naming turns something clinical into something personal. When Dave is "naughty," it's because "he's a boy and boys are naughty." Wendy behaves better because she's a girl. This humour transforms something overwhelming into something she can laugh about.

Lillie's advice to anyone facing stoma surgery is direct:

"Be brave."

She said it's hard to explain bravery in words. Sometimes it's simply accepting what's happening and taking care of the next thing.

Dave's beginning — when "managed" doesn't mean "fixed"

Dave was formed in December 2020, just before Christmas and in the middle of the COVID pandemic. Lillie had lived for years with severe chronic constipation. Medications and procedures were tried, but eventually the family reached what Emma calls "the end of the line."

A stoma doesn't always "fix" a problem — sometimes it helps manage something that can't be fixed. For Lillie, the colostomy



allowed bowel output to move, bringing an essential improvement in quality of life.

But "managed" doesn't mean easy.

Over time, new issues emerged. Lillie began passing large amounts of mucus rectally. In August 2025, she underwent major surgery to remove her rectum. She spent two weeks in hospital, this time in adult care, with Emma by her side.

Dave remains unpredictable. Over the past year, Lillie has experienced what the family call "explosions" — sudden, dramatic emptying often preceded by severe cramps. Afterwards, the pain eases, but during it the experience can be painful, frightening and exhausting.

These episodes also affect Lillie's diabetes. When her bowel rushes, her blood sugars can drop rapidly, requiring close monitoring and intervention. Managing interacting conditions creates a unique fatigue — because the issue is never just one thing.

Wendy's rescue — no more tubes down the leg

If Dave's story is complicated, Wendy's is, in many ways, a success.

For years, Lillie lived with a neuropathic bladder. Treatments escalated from medication to Botox injections and finally to a suprapubic

catheter. For seven years she underwent general anaesthetic every twelve weeks for catheter changes. Eventually she needed a leg bag on constant free flow — uncomfortable and visible.

Then came repeated blockages. The catheter clogged with mucus and tissue. Emma flushed it several times a day. School staff did the same. When it fully blocked, Lillie was rushed to hospital for painful emergency treatment.

"There was no quality of life," Emma says.

In January 2022, surgeons created Wendy through an ileal conduit urinary diversion. The operation lasted seven and a half hours and was followed by serious complications: ileus, severe vomiting, electrolyte collapse, seizures and time in HDU. Emma lived through this alone due to COVID restrictions and still describes it as traumatic. Lillie thankfully remembers little of it.

Today, Wendy is "very well behaved." Lillie can empty her bag herself, giving her independence and when asked how she feels about this she says:

"Better! No more tube. I can wear whatever I want."

The comfort, dignity and freedom Wendy has brought are a huge relief and a small victory in the number of battles Lillie and her mum face every day.

The smile that inspires a community

Another one of Lillie's superpowers is her infectious smile.

Her Facebook page, Miss Lillie's Journey, has more than 6,400 followers — her "fans." Emma shares hospital updates alongside everyday moments: dogs, café trips, boredom, bravery and life in between. On Rare Disease Day she described Lillie as "Rare, unique, inspirational," before returning to what defines her:

"Yet that famous Lillie SMILE shines through."

The support goes both ways. Living with a rare condition can be isolating, but online Lillie and Emma have created a space where others feel understood. Lillie sometimes shares openly when she's in pain or exhausted — a reminder that being inspirational doesn't mean pretending to be fine.

Love, friendship and special moments of joy

Lillie's life isn't only hospitals and care plans. She has a boyfriend, Steven, and they've been together for seven years. Steven also has additional needs, so when they go to cafés or the cinema, Emma is always nearby to support them both.



Many people with stomas fear they won't be loved. Lillie's story challenges that. Her stomas are part of her life, not the end of it. Steven makes a point of asking after Dave and Wendy — something Lillie clearly appreciates.

One of the highlights of Lillie's life came in 2019 when she was granted a Make-A-Wish trip to Disney World in Florida for her 15th birthday. The family stayed at Give Kids The World Village, and everywhere Lillie went she wore her special lanyard as a "wish child." Mickey Mouse was — and still is — her absolute favourite. Years later, she still talks about Mickey with the same excitement.



She also loves music (from Olly Murs to Mr Tumble), sensory lights, Roblox, Disney films and animals — especially giraffes. She has two dogs: Rufus, a gentle black lab who comforts her when she's unwell, and Lola, a springer spaniel who bounces through life waiting to play.

Family — the close-knit safety net

Behind every superhero is a team — and Lillie's is close-knit and devoted. Her dad Phil is a steady presence, even with his own health challenges. Her older brother Michael treats her exactly as any big brother should: winding her up, teasing her, and making her feel like an ordinary little sister.

Hannah, Lillie's big sister, is "my safety net" Emma says. If Emma is too unwell, or stretched thin by her other caring responsibilities, Hannah steps in without question. She is deeply involved in Lillie's care and is always willing to be part of the support team. Emma calls it "girl power in the truest sense."

"No matter what happens to me," Emma says, "I know Hannah will make sure Lillie is cared for." That certainty — the knowledge that Lillie will never be without someone who loves her and knows how to help her — is one of the most reassuring facts in Emma's life.

Now Hannah has exciting news of her own: she is expecting a baby boy and moving close by. Lillie is thrilled to be an auntie soon. The next generation is arriving — and the family's circle of love is only growing wider.





MR IAN DANIELS FRCS

Adhesions and Blockages

Colostomy UK's President, and renowned Colorectal Consultant, Mr Ian Daniels FRCS, talks us through adhesions and blockages, explaining what can be done to reduce the risk of experiencing problems with either.

What are adhesions?

Abdominal adhesions are bands of scar tissue that form between organs and tissues inside the abdomen. They most often develop after surgery, but can also occur after infection, injury, or internal bleeding.

Adhesions may cause chronic abdominal or pelvic pain, small bowel obstruction, and, in some cases, female infertility.

What causes abdominal adhesions?

Most adhesions develop after abdominal or pelvic surgery as part of the body's normal healing process, usually within the first 3 to 5 days. The risk is higher after lower abdominal, bowel, pelvic, or gynaecological surgery, especially emergency surgery or surgery involving infection.

Keyhole surgery (laparoscopic or robotic) usually causes less tissue trauma than open surgery, so it may reduce the risk, but any abdominal surgery can lead to adhesions. The extent of adhesions varies between individuals and does not always match the severity of symptoms.

Less common causes include pelvic inflammatory disease and radiotherapy to the pelvis.

How do adhesions cause obstruction?

Adhesions can trap or kink the small bowel, restricting the movement of bowel contents and causing a blockage. This is called adhesional small bowel obstruction (SBO).

Small bowel obstruction can occur at any time after surgery. However, we are now thankfully seeing this a lot less due to the changes in surgical techniques. For example, ensuring surgeons avoid irritants to the bowel, less tissue and organ handling, and an increased use in keyhole surgery in place of open surgery.

Although modern surgical techniques have reduced the risk, obstruction can still occur many years after previous surgery, especially in older people who underwent open surgery for procedures which today are more commonly performed using keyhole surgery, such as appendicectomy, cholecystectomy, or hysterectomy.

Signs and symptoms of adhesional small bowel obstruction

Most adhesions cause no symptoms, but when they do, the most common complaint is ongoing abdominal or pelvic discomfort.

It may mimic other conditions such as uncomplicated diverticulitis, a urinary tract infection or functional bowel problems, such as constipation.

Symptoms of bowel obstruction may include:

- » severe abdominal pain or cramping ("colic")
- » abdominal swelling
- » nausea and vomiting
- » loud bowel sounds (although in some people, the abdomen can be silent)
- » inability to pass wind or faeces (often referred to as "absolute constipation")

A person with these symptoms should seek medical advice immediately, as earlier assessment and treatment can improve a patient's outcomes.

How are adhesions and obstruction diagnosed?

There is no scan or test that can reliably confirm adhesions themselves. They are usually only seen during surgery.

Bowel surgeons are sometimes asked to help other colleagues such as gynaecologists and urologists with surgery when extensive adhesions are identified.

Adhesional bowel obstruction is now usually diagnosed with a CT scan, which shows enlarged bowel loops above the blockage and empty bowel below it.



As surgeons, we often describe adhesional obstructions like the development of an accident on a motorway. Once the motorway is blocked, the traffic gets held up and the drivers may get irritated (colic). Nothing passes through, so then the traffic jam gets longer (nausea) until ultimately some drivers turn around and go back the way they came (vomiting). Once the blockage has been relieved and the "traffic begins to flow again" the delayed traffic speeds through past the point of obstruction and the bowels are often loose and in a hurry!

Most episodes of small bowel obstruction settle with careful monitoring and supportive treatment, but a small number of patients (less than 10%) will need surgery to relieve the blockage.



How are they treated?

Planned surgery for adhesions is uncommon because further surgery can create more adhesions and carries a risk of bowel injury.

When adhesions are causing "transit problems" (i.e. slow bowel movements), symptoms may improve by:

- » eating smaller meals
- » chewing food well
- » spacing meals out during the day
- » drinking plenty of fluids

Can abdominal adhesions be prevented?

Adhesions are difficult to prevent completely. However, modern surgical techniques have reduced the risk. Keyhole surgery, gentle tissue handling, reducing blood loss, and lowering the risk of infection all help.

However, all types of surgery, including keyhole surgery, carry some risk and patients who suffer from complications such as a post-operative infection or those who require further emergency surgery during recovery, have increased risks of all complications - including those related to adhesions.

Many products and methods have been tested to prevent adhesions, but none are used routinely in all cases. In practice, we as surgeons aim to minimise tissue trauma and infection during surgery.

Historically, it was the use of talcum powder or starch inside surgical gloves that was associated with adhesions, however, these were removed a long time ago now I'm pleased to say!

How to avoid blockages

Stoma output and consistency depend partly on the type of stoma formed (ileostomy versus colostomy). After surgery, good nutrition is important for healing as the body needs more calories and protein.

To help bowel function and reduce the risk of blockage:

- » eat regularly and in a relaxed setting
- » have small meals more often
- » chew food well
- » drink plenty of fluids, especially in hot weather
- » eat a balanced diet, including fruit and vegetables, unless certain foods cause problems
- » take regular exercise

Some people notice extra wind at first, but this often settles with time. During this time certain foods should be reintroduced to your diet gradually, as eating sensibly is important to encourage regular bowel function.

Your stoma care nurse can also give you the appropriate advice to meet your dietary needs, and Colostomy UK also has plenty of helpful information on offer too (see below).

But more than anything, it's important to remember eating should still be enjoyable, and with a little care, there's no reason this shouldn't remain the case.

For more dietary advice, visit Colostomy UK's website, where you can find a booklet on 'Healthy Eating' amongst lots of other information.





fundraising



Megan Lowden
Fundraising Executive

Fighting in Colostomy UK's Corner

Jamie Creek took on Charity Fight Night in March supporting Colostomy UK, raising an incredible £600 and winning his fight too! Living with a colostomy following serious ill health and multiple operations, Jamie wanted to use his experience to raise awareness and show that not all disabilities are visible. With boxing being a huge part of his life, the event was a fitting way to prove that having a stoma doesn't stop you from achieving your goals.



£600 Raised

Tackling temperance

Graham took on the challenge of Dry January in support of both Colostomy UK and the Bradley Lowery Foundation, raising vital funds for families navigating life with serious medical conditions. His motivation was deeply personal: both he and his partner Chloe have received invaluable support from Colostomy UK following their young son Henry's stoma surgery. Henry is still living with a colostomy, making the charity's work especially close to their hearts.

Through his efforts, Graham raised an incredible £371, a fantastic achievement that will help ensure more parents in similar situations receive the guidance, reassurance and support they need.



£371 Raised

Rising to the Challenge

Mel and Emma took on the challenge of climbing Mount Snowdon (aka Yr Wyddfa) in May to raise awareness for Colostomy UK, inspired by their dad's long and difficult journey with diverticulosis and diverticulitis. Following major surgery in March 2024, which resulted in a stoma, they witnessed his incredible strength and resilience during recovery. Through this climb, they hope to honour his bravery, share his story, and help shine a light on the realities of living with a colostomy. Mel and Emma are up to a fantastic £435 raised at the time of print with their total still rising!



£435 Raised

Community Coming Together

In March, we were once again grateful to receive a generous £250 donation from Leighton Buzzard Freemasons group in support of our core services. Ongoing support like this plays an important role in helping us continue to be there for everyone living with a stoma.

If you are part of a community group or organisation, why not consider nominating Colostomy UK as a beneficiary? You can also get in touch with our team at getinvolved@colostomyuk.org and we will be happy to support you every step of the way.

Support Colostomy UK Now and Into the Future

Leaving a gift in your will is a meaningful way to support people living with a stoma in the future. Any gift, large or small, can help ensure support services are there for those who need them, grow programmes that build confidence and wellbeing, and keep trusted information available to all. It is a simple way to make a lasting difference.

We have partnered with FreeWills.co.uk to offer a free and easy way to write or update your will, with guidance throughout and the reassurance that it will be checked by a solicitor. You may choose to leave a fixed amount or a share of what remains after providing for your loved ones. Gifts to charity are also exempt from inheritance tax, which can reduce the overall tax on your estate.

If you are thinking about leaving a legacy, it is always best to seek advice from a qualified solicitor to ensure your wishes are clear. If you

do choose to support Colostomy UK in this way, we would be delighted to hear from you. Contact our team on getinvolved@colostomyuk.org to discuss this with us.

"In leaving a legacy to Colostomy UK, I feel happy that I am helping ensure that future generations of people with stomas will also have access to the incredible support that I received from the charity."

Jackie, long standing supporter and volunteer of Colostomy UK



Corporate Fundraising

In January, we were delighted to receive a generous £10,000 grant from The Childwick Trust to support the continuation of our core services. This funding will help ensure we can be there for people at every stage of their stoma journey, offering reliable support, guidance and reassurance whenever it is needed.

Grants like this make a real and lasting difference, enabling us to reach more people, strengthen our services and continue providing vital support to our community. We are incredibly grateful to The Childwick Trust for helping us extend our impact even further.

From Bowel Cancer to Brighton's Coastline

Julian took on the Brighton Marathon less than two years post Bowel Cancer diagnosis and stoma surgery. After completing a couch to 5k programme at the start of 2025 he decided to celebrate his recovery by running 42k instead! Julian has raised over £5,000 in vital funds for both Colostomy UK and Macmillan, two charities that made a positive change to him during his recovery. In Julian's own words, "Colostomy UK is my go-to charity for advice on managing a Stoma. I get access to groups that share the emotional rollercoaster that comes as part of living with a Stoma". What an incredible achievement!



£5,000+ Raised



Active April shout out

A huge shout out to our Active April fundraisers who dedicated their month to taking part, raising vital funds and awareness for the 55 individuals who undergo stoma surgery every day in the UK. A wonderful 40 individuals came together to Step Up for Stomas throughout the month of April. Some of the creative challenges people chose to take on included doing 55 reps of ab exercises each day, to committing to 5,500 steps every day. One participant even decided to run 5.5km to celebrate her 55th birthday – very apt indeed!

Facebook Fundraisers

Since our last update, an awesome 10 people on Facebook chose to set up fundraisers to celebrate their birthdays and other personal events and raised £1,000 collectively!

Facebook gives its users the option to ask for donations for a special cause for the duration of the online celebrations (usually a period of about two weeks). So please do keep us in mind if you have a birthday or special occasion coming up!



My Journey With a Parastomal Hernia

For Kev Harvey-Austen, in many respects life with a stoma has been an easier journey to navigate than life with his parastomal hernia.

When my stoma was formed in April 2016, it wasn't after months of planning or gentle preparation. It happened on my very first hospital visit, after sixteen years of battling Crohn's disease. One moment I was being assessed; the next, I was in emergency surgery.

I woke up with a stoma, a new reality, and a body that felt unfamiliar. Like many people in that situation, I focused on survival and recovery. I didn't yet understand how vulnerable the area around a stoma can be, or how quickly complications can develop.

What I didn't expect was that the next challenge would arrive almost immediately.

The Hernia That Appeared from Day One

Right after surgery, I noticed a lump forming around the stoma. At first, I assumed it was normal swelling. But then came the leaks - not occasional, but constant. The bag wouldn't sit right, the seal wouldn't

hold, and I found myself changing appliances far more often than anyone had prepared me for.

When I raised concerns, I was told the hernia was "rare" and nothing to worry about. I was reassured that it would settle. No one mentioned support garments, risk factors, or early assessment. In the end, I identified the hernia myself through information available on the website of the medical clothing specialist, Comfizz, rather than through clinical guidance.

That early dismissal shaped everything that followed.

When a Hernia Starts Controlling Your Life

The hernia didn't stay small. It grew quickly, and with it came more leaks, more discomfort, and more disruption. One day I had eight leaks - eight full changes, eight moments

of frustration, eight reminders that something was wrong.

Some memories stay with you. One of mine is an air show day out with my daughter. A leak happened suddenly, painfully, and my skin began to bleed.

What should have been a joyful family moment became a reminder that my body was struggling and that I was constantly one step away from embarrassment or pain.

A hernia isn't just a bulge. It affects how you walk, how you sit, how you

sleep, how you dress, and how you plan your day. It affects your confidence, your independence, and your sense of control. It becomes a constant presence - one you didn't choose and can't ignore.

The Fight for Repair - and the Complications That Followed

When the hernia became impossible to manage, I pushed for repair. But this was during COVID, when elective surgeries were paused and resources were stretched. Keyhole surgery wasn't available, and I found myself in a long cycle of waiting, asking, and being told "not yet."

The medical decision to delay the repair wasn't based on how the hernia affected my life - only on its size. But size isn't the whole story. Activities, strain, and daily function matter too. I learned that the hard way.

At one point, after being repeatedly refused repair, I tried to strengthen my core with sit-ups. No-one had warned me that sit-ups with a stoma and hernia combination can be dangerous. The hernia strangulated. Suddenly, the repair that had been considered "non-urgent" became unavoidable.

The surgery that followed was far more complex than it might have been if the hernia had been addressed early. Recovery took more than six months physically, and much longer mentally. The experience left scars that weren't just on the surface.

The Emotional Weight That Isn't Always Spoken About

Living with a hernia isn't only a physical challenge. It affects your sense of identity and your relationships. In the early years, I struggled to understand my future purpose and worth. I felt like my body had betrayed me twice - first with Crohn's, then with the hernia.

The strain didn't stay contained to my health. It contributed to the breakdown of my 18-year marriage. Chronic illness doesn't just test the person living with it; it tests the entire support system around them. When you're dealing with pain, leaks, fear, and uncertainty, it becomes harder to show up emotionally in the ways you once did.

These are the parts of the story people don't always talk about. But they matter. They're real. And they're part of why early intervention isn't just a clinical issue - it's a human one.

What I Wish I'd Known Sooner

Every ostomate's experience is different, and nothing replaces personalised medical advice. But there are things I wish someone had told me in those early days - things that might have changed the path I ended up on.

- » A lump right after surgery isn't always "normal swelling." If something feels off, push for assessment.
- » Leaks may be a sign that something needs attention. They're not just an inconvenience; they can indicate underlying issues. You may need an assessment of your products or your technique.
- » Support garments matter. Early fitting and proper guidance can help protect the abdominal wall. Your stoma nurse can offer you a support belt fitting or refer you as required.
- » Sit-ups and similar exercises can be dangerous with a hernia. Safe movement guidance is essential.* Please seek advice from your stoma nurse/physio on the correct exercise programme for you.
- » Don't accept "it's not big enough" as the only measure for repair. Daily function, pain, and quality of life matter too.
- » Advocacy is not being difficult. It's protecting your long-term health.
- » Mental recovery can take longer than physical recovery. And that's okay.

A Message to Anyone Living with a Stoma or Hernia

If you're newly adjusting to life with a stoma, awareness isn't about fear - it's about empowerment.

Understanding risks early can help you protect your future self.

If you're already living with a hernia, know that you're not alone. The frustration, the exhaustion, the emotional weight - they're real, and they're valid. Your experience matters, and your voice deserves to be heard.

And if you're fighting for assessment, repair, or support, keep going. Your quality of life is worth advocating for.

Your body has carried you through more than most people will ever understand. That resilience is something to be proud of - not something to hide.

*Advice on exercising safely with a stoma can be found Colostomy UK's Exercise Information Page

You can also ask Tidings' resident fitness guru, Jo Prance, exercise related questions by emailing us at:

Visit Kev's blog to hear more about his experiences as an ostomate

Editor@ColostomyUK.org.uk



Stoma Care While in Hospital

BY JACKIE DUDLEY



Regular Tidings' contributor, Jackie Dudley, recently underwent surgery for a health issue which didn't have anything to do with her stoma. This got us thinking – how should ostomates manage their stoma care needs while in hospital for a completely unrelated issue? Jackie shares her experience along with some helpful tips for anyone who may find themselves in a similar predicament.

The reason for the hospital stay and initial stoma-related challenges

After years of back and leg pain, I was finally offered lumbar decompression surgery to relieve the symptoms. I was warned I'd have a spinal wound with a dressing that had to stay dry for two weeks, meaning no showering! I would also struggle to sit comfortably, needing cushions and support.

That immediately made me think about my stoma care. My usual routine of emptying my pouch from a seated or kneeling position simply wouldn't be possible after surgery. I therefore decided in advance to switch to a closed pouch, which couldn't be emptied but could be removed and disposed of easily when full.

Preparing ahead of the hospital stay

I contacted several companies advertised in Tidings to ask about different closed pouch options. I also spoke with my stoma care team about my plans. I realised I would need to manage everything while standing, ideally near a sink, with somewhere secure to dispose of used pouches and a surface for my equipment.

Normally, with a drainable pouch, I rinse with warm water to extend wear time. After surgery, I realised that wouldn't be at all practical. Instead, I planned to use a closed pouch. Standing at the basin, and tucking a disposal bag under the pouch, I would spray the adhesive remover and let the full pouch drop straight into the bag. I could then clean the stoma and apply

a new pouch before sealing and disposing of it. I practised this method at home, so I felt confident with my new routine before hospital admission.

I informed the hospital stoma care department of my surgery date and the details of the operation, and I made sure they had my contact numbers if they needed to find me after the operation.

Next up, I contacted my GP who then submitted a prescription for more of my pouches than I would usually need, in case these might be needed during my hospital stay. I also notified my delivery company to explain the situation, and ensuring everything would arrive before I went into hospital.



During the hospital stay

On admission, I made sure the ward sister and nurses knew about my stoma and how I planned to manage it. I stayed in bed for five days after the operation but thankfully I was able to walk to the toilet with a frame and a nurse. Although sitting and lying were uncomfortable because of my back wound, I could stand, and that meant I was able to change my pouch independently. My preparation paid off!

Before going in, I packed a dedicated "bathroom bag" (ideally a zipped bag with handles) ready for each change. Mine contained:

- » Pouches
- » Disposal bags
- » Wipes
- » Protective pads
- » Adhesive remover spray
- » Scissors
- » Plus any accessories I needed.

I also kept a second supply bag in my bedside locker with extra supplies, plus my prescription details and key contact numbers. Having spare supplies close by meant I felt prepared for accidents, delays or a longer stay, and gave me real peace of mind while recovering.

Potential Challenges and Complications

Whatever operation you have, it can affect your stoma. Anaesthetic, new medications, changes in diet and fluid intake... all of these may lead to either diarrhoea or constipation. I experienced both.

When I became constipated there was no output and the area around my stoma felt hard and uncomfortable. I increased my fluids, kept moving as much as I could, informed the nurses and requested

a mild laxative. I also used a heat pad over the stoma area and chose foods like greens and salad to help stimulate my bowel. Anticipating output returning, I protected the area with my famous puppy pad technique to prevent leaks.*

I later had diarrhoea, with the pouch filling quickly. As I still couldn't bend to empty into the toilet, I used a jug in the basin and switched back to a drainable pouch, which made management much easier. If using a closed pouch, you can release it into a disposal bag or container, then empty it into the toilet.

I adjusted my diet to help thicken the output and, over the following days, things settled back to normal. The ward nurses will notice these changes and you can always ask for the stoma care team to review you for reassurance as well.



Going home

If you have family support, accept their help while you recover and keep in touch with your stoma care nurses as your strength returns.

As I live alone, I looked into what support I could have after discharge, but found it difficult to get clear information, so I arranged a short stay in a rehabilitation centre. For me, this removed the worry of coping at home straight away. Staff helped care for my wound, washing and dressing

(as I had to keep the dressing dry), and supported my mobility, while I was still able to manage my stoma independently.

I began physiotherapy immediately, with daily exercises to rebuild strength and confidence. Having meals prepared and practical help available meant I could focus on recovery rather than daily tasks like cooking and personal care.

After two weeks, I returned home with a live-in carer for a short period. This private care made a significant difference to my recovery but it was also not cheap, and I realise it is not an option open to everyone.

Thankfully, social services is also on hand to provide support to everyone. Their staff helped me gain confidence and highlighted the many causes of accidents around the house, and how to avoid these.

Nearly four months on, I am still improving, but my stoma has settled back into its usual routine, and I have returned to a drainable pouch. I am now looking forward to getting back to normal life, and in particular, my gardening.

***Read about Jackie's puppy pads solution to leaks in the Winter 2024 edition of Tidings. Also available via our website.**



You can help Colostomy UK and benefit too!

Just two easy ways to support us are through our lottery, and by recycling unwanted clothing and household items.

Win up to **£25,000!**



'A lottery entry costs just £1 and at least 50p comes directly to Colostomy UK.

Visit www.colostomyuk.org/get-involved/fundraising/unity-lottery/ for more information and to start playing.

Bring the charity shop to your doorstep!

iCollectClothes operates a charity collection service in major UK cities to pick up your donations of clothes and small domestic items, free of charge, on a date convenient to you. Book it online, leave it outside:

www.icollectclothes.co.uk



For any queries please contact us: getinvolved@colostomyuk.org or call 0118 939 1537

stomafriendlytoilets.com

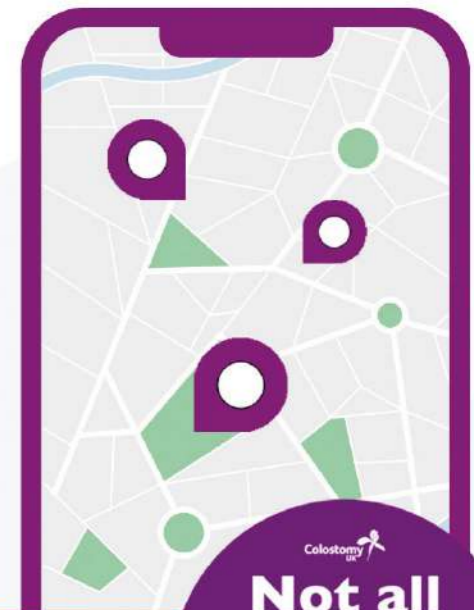


Our NEW **Stoma Friendly Toilets Finder!**

Over **1000 venues** across the UK!

Find **stoma friendly toilets** near you. Places designed to give you the space, comfort, and dignity you deserve.

FIND TOILETS NEAR YOU



Not all disabilities are visible
#stomafriendly



Scan the QR code or visit: stomafriendlytoilets.com

Help us continue to grow our **FREE Stoma Friendly Toilets Finder**

DONATE TODAY

colostomyuk.org/donate



GetInvolved@ColostomyUK.org

Stoma Helpline: 0800 328 4257
Stoma Admin Line: 0118 939 1537



Giovanni Cinque
Marketing & Campaigns Manager
GetInvolved@ColostomyUK.org



campaign news

Colostomy UK's Marketing and Campaigns Manager, Giovanni Cinque, talks us through all the latest campaign news and how these are making a positive difference in the stoma world.



Stoma Friendly Toilets campaign update

We're really pleased to share that both Morrisons and B&Q have joined our Stoma Friendly Toilets campaign, with all the accessible toilets in their UK branches meeting our guidelines. Seeing well known, national brands get behind this is exactly the kind of progress we want to see.

If you live with a stoma, you already know that too often, toilets are simply not set up with stoma care in mind. No shelf, no-where to hang anything, limited disposal options. It's not complicated, but it does make a difference, and when those basics are missing, it shows.

That is why this campaign matters and why having retailers like Morrisons and B&Q involved is such a big step.

Both have recognised that small, practical changes can make a real difference to people's confidence, independence, and day to day life.

This is also about raising awareness. When big brands take action, it helps get more people talking and helps others understand why this matters.

A big thank you to Morrisons and B&Q for listening and getting involved. We hope this encourages more organisations to take a look at their own facilities.

You can find Stoma Friendly facilities in your area by searching our new Stoma Friendly toilets finder online www.stomafriendlytoilets.com



New Stoma Prescription Services and what this could mean for you

As part of changes in how NHS services are organised, some areas in England are introducing central prescription services for medical appliances such as stoma supplies.

These services are being developed by Integrated Care Boards (ICBs) who are the local NHS organisations responsible for planning and funding health and care services in your area.

Central services are designed to make repeat prescribing more consistent, streamlined and clinically supported across GP practices and community care.

In practice, this means that the way you place your monthly order for stoma products may change but it shouldn't affect your choice of products or delivery company.

What are central prescription services?

Central prescription services (sometimes called Appliance Prescription Management Services),

act as a central point for managing repeat prescriptions for medical appliances, including stoma and bowel management products.

These services are usually:

- » Commissioned by your local ICB
- » Managed by specialist teams, including advisers and nurses
- » Responsible for issuing and reviewing appliance prescriptions on behalf of GP practices
- » Designed to ensure prescriptions are clinically appropriate and correctly aligned with your needs

For example, in some areas, prescriptions for stoma and related equipment are centrally reviewed and authorised by specialist nurses before being sent to your chosen dispenser.

How the ordering process works :

When you place your order with a central prescription service, you will typically:

- » Contact the service by phone or online to request your supplies
- » Confirm the products and quantities you need
- » Confirm your choice of delivery or dispensing company
- » Be asked a small number of questions about how you are managing your stoma and whether you have had recent contact with a stoma care nurse

These questions are intended to make sure you are supported properly, identify any issues you might be facing, and help connect you with clinical support if you need it.

Once your prescription is authorised, it is sent to your chosen supplier, and your products are delivered as before.

Your choice of delivery company

It's important to know:

- » You have the right to choose who supplies and delivers your stoma products
- » You do not have to change your delivery company if you are happy with your current one
- » Central prescription services should ask you to confirm your nominated supplier when you place an order

If you wish to continue using your existing provider, simply tell the central service when asked.

What if you are asked to change supplier?

Your right to choose your supplier is protected by the NHS Constitution. You should not feel pressured to change your delivery company if you don't want to. If alternative providers are mentioned, you can clearly state your preference to stay with your chosen supplier, and the service should support that choice.

Once your delivery company is confirmed:

- » Your supplies should continue to arrive at your home as usual
- » You may not need to contact your delivery company each month, depending on how your prescription is arranged
- » You should continue to receive the products that meet your clinical needs

If you have concerns

If you are unsure about changes to a prescription service, feel pressured to change supplier, or experience problems accessing your supplies, you can:

- » Contact the central prescription service for clarification
- » Speak to your stoma care nurse or GP
- » Seek support and advice from Colostomy UK



Your Letters and Emails

Here's a summary of your most recent letters and emails.



Thanks for Tidings. The last issue was great as usual. Being a urostomate, the article on urostomies was of particular interest. This said, point 7 recommended using wet wipes. My stoma nurses are against their use, instead recommending a dry wipes dipped in hot water. So far, I have managed to avoid infections.

Regards

Merv

We followed up with Merv's query and wanted to offer the following clarification:

1. Dry wipes are the preferred choice and kinder to the skin around the immediate stoma and general dermis. Should be used when cleaning (with water) and then drying;

2. Wet wipes are useful when out and about - especially when water facilities are not to hand or the bathrooms/toilets are less than hygienic;

N.B. Choose "Water wipes" or sensitive wipes if needing to use wet wipes, as these contain fewer additives.

Many thanks for another edition of Tidings, as ever packed with fascinating, useful and thought provoking articles. My copy is read by three stoma families!

The articles on low FODMAP were very interesting. I have suffered from IBS for many years. When I had my bowel cancer surgery in 2014 the nurses told me: "If you had IBS before your surgery, you'll still have it afterwards". Having been given a stoma, this was not good news.

After the first disastrous few months, I discovered references

to the low FODMAP diet but my NHS dietitians knew nothing about it. My wife then discovered a low FODMAP trained dietitian in Belfast, within travelling distance, and my life changed immeasurably from then.

I also suffered from a lot of anxiety, and I discovered a wonderful homeopath here in Northern Ireland, who is caring, insightful and very skilled.

Many thanks for everything you do at Colostomy UK.

John Niven

John has said he is happy to share further information on any of the above if it might be useful to others. Please email Editor@ColostomyUK.org and we will arrange for you to be put in touch.



Got something you'd like to share? 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.

Happy writing!

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

Bedfordshire

Wing Stoma Support Group
Clare Hall T: 0118 961 8297
E: clare.hall@clinimed.co.uk

Berkshire

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

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

Bristol

Bristol Ostomy Self Support (BOSS)
John T: 01934 863679
E: j_batt@btinternet.com

Nailsea and District Ostomy Group
Peter T: 07355 038255
E: johnandjames4help@googlemail.com

Buckinghamshire

High Wycombe Stoma Support Group
Clare Hall T: 0800 585 125 (clinimed)
E: clare.hall@clinimed.co.uk

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
E: aww100gun@aol.com
W: www.ostomistics.org

Cheshire

Warrington Stoma Care Support Group
Sue Guilfoyle T: 01925 946348
E: bchft.warringtonstomacareteam@nhs.net

Christchurch

StoMuchLove Christchurch
Jess E: stomuchlove@gmail.com

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

Cornwall

Cornwall Bowel Cancer Support Group
James T: 01872 241 145

Lanhydrock Ostomist Group
Mandy Rowe T: 07980 432072
E: murphy.rowe781@btopenworld.com
Ceri Moore T: 07871926631
E: ceri.moore75@outlook.com

Cumbria

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 Youthful Ostomates)
Yvette T: 07800646006
E: fishysderbyshire@gmail.com

Mercia Inside Out Stoma Support Group
E: merciassgroup@gmail.com
Sally T: 07500 441 442

Devon

West Devon Stomates
T: 07736936731
E: Scarlett@westdevoncvcs.org.uk
Facebook West Devon Stomates

Devon IA

E: devon@iasupport.org

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

Plymouth & District Bowel Cancer Support Group
Rita T: 07855571840
E: admin@plmdistbcsg.com

Dorset

CUPID Colostomy Urostomy Pouch Ileostomy Dorset Support Group
Jenny Pipe T: 01202 740440

Durham

Durham OOPS (iliOstomy, colOstomy and UrOstomy Patient Support)
Claire T: 07596 714024
E: oopsgroup@outlook.com
W: www.durhamlocate.org.uk

Essex

Connect Harlow & District Stoma Group
Alan T: 07799 220207
E: comeconnectwithus@gmail.com

Mid Essex Stoma Support Group
Paul Fox T: 01245 441 894
E: fox.paul@hotmail.com

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

Optimistic Ostomist Peer Support (Oops) Nursing Team
T: 01642 944324
E: stees.stoma@nhs.net

Castlepoint Stoma Support Group
Sally T: 07779139953
Sue T: 07802773458
E: cpstoma@aol.com

STEPS - Stoma Essex Patients Support
T: 01268451937 or 07752234516
E: stepsexsex@gmail.com

Gloucester

Gloucester Ostomates
Julie T: 07979129001
E: juliematthew@hotmail.com

Gloucestershire

Stroud Stoma Group
Kathryn Whitehead T: 07802421190
E: kathrynswain@hotmail.co.uk

Hampshire

Replummed Stoma Support Group
W: www.replummed.me

Solent Ostomates Support Group (S.O.S.)
Roy T: 07971721652
E: solentostomates@hotmail.co.uk or 200rtb@gmail.com

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



The Hampshire Ostomates Support Group
Nicki Beare T: 07771 558458
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

Herefordshire

Herefordshire Stoma Support Group
E: herefordstoma@gmail.com

Hertfordshire

Friends with Stomas - Welwyn Garden City
Tracey T: 07557 402495
E: Tracy at fwswg@gmail.com

Ostofriends Stoma Support Group
Peter/Lynne/John/Nicola
E: ostofriends@gmail.com
T: 07596 748376 or 07501 137511
W: ostofriends.co.uk

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

Friends with Stomas
Mel North T: 07939 069833
E: friendswithstomas@outlook.com
W: friendswithstomas.co.uk

Isle of Wight

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

Isle of Wight Stoma Support Group (Baguette Group)
Debbie Lumley T: 01983 741384
E: debbieattwiggsg@gmail.com

Kent

Ashford Stoma Support Group
Malcolm Jones T: 07709 534463
E: malcolm-assg@hotmail.com

Canterbury Stoma Support Group
Beth T: 07999667515
E: canterburysg@gmail.com

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 T: 01304 821132 or
07720723445

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

Maidstone Stoma Support Group
T: 01622 224305

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

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

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

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@sehc.org.uk

Bowel & Other Cancer Support Newham
T: 020 8553 5366

Eltham's Stoma Support Group
Tara T: 07970563890

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 Stoma Support Group
Stacy or Nelson T: 020 8535 6563
E: bartshhealth.stomanursewxh@nhs.net

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

Middlesex Inside Out Stoma Support Group
Barry T: 07777 667367 or 07811 084514
E: Info@iossg.org.uk,
W: www.iossg.org.uk

Norfolk

James Paget Ostomy Support Group
Sheila T: 01493 600 934
E: hshowlett@aol.com

The King's Lynn and District Ostomy Support Group
T: 01406 363756 or 01553 775698

Stoma and Reconstructive Surgery Social Support Group STARS
E Roberts
E: elrattle@hotmail.com

Northamptonshire

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

Northumberland

Berwick Ostomy Support Group
Bobbie Minshall T: 07714 479 320
E: lacemaker56@gmail.com

Nottinghamshire

Bassetlaw Stoma Social
Sarah and Sue
E: McManus.s1@sky.com

North Notts Stoma Support Group
Tore and Nicky Norman
T: 07956955105 or 07985163477
E: normanwilliam79@gmail.com

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

Bag Buddies
Susan T: 07519 171161
E: 134powerhouse@gmail.com

Shropshire Bums on Tums Stoma Support Group
Peter T: 07704137777
E: peter.hollins1@btinternet.com

Somerset

Waitrose Ostomates Support Group
Fiona Rogers T: 01225 873657
E: ruh-tr.stomatherapy@nhs.net

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: 07544 978815
Jennie T: 01394 284637
Helen T: 07941 738630
E: denisonianlin@gmail.com

James Paget Ostomy Support Group
Sheila T: 01493 600 934
E: hshowlett@aol.com

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

Replumed Support Group
Debbie, Rachel, Felichi T: 03006136301
E: fhft.stomacareteam@nhs.net

Sussex

Brighton & District Support after Stomas (SAS)
Virginia Keefe T: 01273 723775
E: virginiakeefe@uwclub.net

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
E: ghnt.stomacarenurses@nhs.net

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

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

West Midlands

Birmingham, IA
Kalpana
E: kalpana.mannota@iasupport.org
W: birmingham.iasupport.org/events

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

Wiltshire

Ostomy Mates
Mike Seed T: 07973 307726
E: m.p.seed@inceutics.com
W: www.swindon-ia.org.uk

Wessex Stoma Support Group
Sally or Ken T: 01980 611978
or 07485 574311
E: info@wessex-stoma.co.uk
W: wessex-stoma.co.uk

Wirral

Sally's Stoma Support Group
Jo Woods T: 07956 216218

Worcestershire

Kidderminster & District Collossus Support Group
Brendon T: 07850 269758

Yorkshire

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

Airedale Stoma Support
Sue Hall T: 01535 646 373

Barnsley Ostimates Support Group
John Holmes T: 07980 388966
E: jkhminor2@gmail.com

Bottoms Up Colorectal & Urology Support Group
John Whelpton T: 07974 657 146
E: midyorks.bottomsup@gmail.com

Bradford Stoma Support Group
Lisa Hall T: 07552 276 747

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

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

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

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

Sligo

Sligo Stoma Support Group
Mary T: (00)353863608798



Scotland

Ayrshire

Ayrshire & Arran Stoma Support Group
Susan T: 07790929268

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

Angus

Angus Stoma Support Group
Valerie T: 07359766289

Dundee Stoma Support Group
Dolores Johnson T: 01382 740453
E: dolores.johnson@nhs.scot
Nancy Rattray T: 01382 632999
or E: nancy.rattray@maggies.org

Dundee Stoma Support Group
Nicola T: 07801702054

Coatbridge

Providing Ongoing Ostomate Support Scotland CIC
E: info.poosscotland@gmail.com
W: www.poosscotland.co.uk/peer-support-groups

Edinburgh

Edinburgh Support Group - Providing Ongoing Ostomate Support Scotland
E: info@poosscotland.co.uk

Glasgow

Providing Ongoing Ostomy Support Scotland CIC
E: info.poosscotland@gmail.com
W: www.poosscotland.co.uk/peer-support-groups

Greater Glasgow

Glasgow Stoma Support Group
Morag Sinclair T: 0141 779 1322
E: sinclairmorag3@gmail.com

Hamilton

Providing Ongoing Ostomy Support Scotland CIC
E: info.poosscotland@gmail.com
W: www.poosscotland.co.uk/peer-support-groups

Moray

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

North Lanarkshire

Chapelhall Stoma Support Group
E: Anthea at admin@chapelhall.co.uk

Scottish Borders

Stoma Support Group
Fiona Gentleman T: 01450 371 063
E: r.gentleman@sky.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
T: 01633 791 339 or 07504 713 069
E: pip112002@yahoo.co.uk

Mold

3 Bags Full
Sharon Davis T: 07359 267075
Robert Rowley T: 07429 622635
Paul Hunt T: 07802 499049
Lindsay Hicks T: 07545 431723

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

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



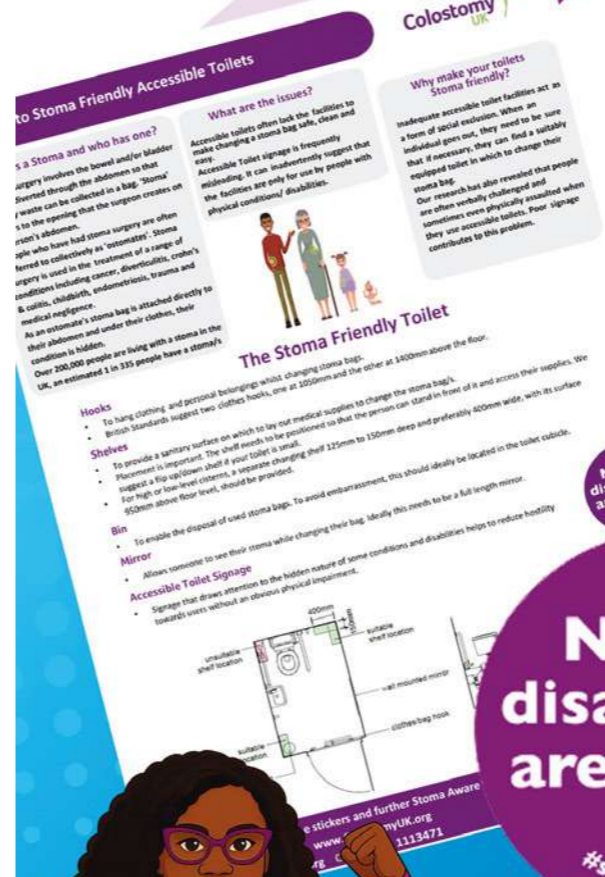
Visit www.colostomyuk.org/donate or go to page 28 for our donation form



How can you help the UK become more stoma aware?

Sign up for your Stoma Mythbusters pack

www.ColostomyUK.org



Will You Help Make Toilets Stoma Friendly? Get your Stoma Friendly Toilets pack now!

Not all disabilities are visible

SCAN BELOW TO GET INVOLVED



www.ColostomyUK.org
getinvolved@ColostomyUK.org





Does someone at home help you with your stoma, or support you emotionally?

We're inviting them to join our free CPD accredited online workshop
Caring for a Person with a Stoma

This 90-minute interactive session is designed for anyone providing unpaid support. That might be a partner, family member, friend, neighbour or unpaid carer who helps you manage your stoma, whether through practical help or emotional support.

Workshop overview:

- 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 with a stoma care nurse
- CPD Certificate

- Held via Zoom**
- Facilitated by a qualified stoma nurse**
- Free for unpaid carers**
- CPD Accredited**

Register using the QR codes below, or get in touch at getinvolved@ColostomyUK.org or 0118 939 1537

16th June 2026
6pm - 7.30pm



13th October 2026
1pm - 2.30pm

