AUTUMN ISSUE | 17

The Get Together 2023!

Catch ups, photoshoot, and family. Find out what our wonderful ambassadors said about our recent Get Together event on p. 18





Pip is a relatively new ostomate, having had her operation last year. She is a 5ft 2" crazy cat lover from Merseyside, who has danced from an early age.

"I know my stuff is in good hands and I'm going to get it quite quick."

Joining Respond has never been so easy, get in touch today and let us do the rest! #JoinTheRespondFamily



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A message from

the Editor



Natalie Jones
Brand Executive

Hello, and a very warm welcome to our autumn edition of Connect. We hope you have had a lovely summer and are looking forward to the season ahead (cue everything pumpkin!).

In this issue we bring you more updates of our 'It's a Family Thing' campaign with a Q+A with our lovely ambassador, Rachel, more inspiring real-life stories, and mouth-watering recipes.

We also share more about our Get Together 2023 event with our wonderful ambassadors, a NEW podcast series and much more.

We're also very excited to share with our readers information about our group product offering through our parent company – head to page 44 to find out more!

As always, I hope you enjoy reading this issue as much as I enjoy creating this for you.

Thank you as always for taking the time to read,

Natalie

We'd love to hear from you ...

Do you have a question? Feedback? Have a story to tell? A subject you'd like to see covered in the next issue? – If this is the case, we'd love to hear from you!

Get in touch with us today via one of the options below



0800 220 300 0800 028 6848 (N.Ireland)



marketing@respond.co.uk



Or, write to us at:
Freepost RTSZ-SLYE-EBTL
Respond Healthcare Ltd,
Greypoint Cardiff Business Park,
Parc Ty Glas, Cardiff, CF14 5WF

Letters to the Editor

At Respond we love receiving our customers' feedback, and so we wanted to share the following words we received after the last issue of Connect® magazine with fellow readers...

Dear Respond,

"Eakin and Respond have been life savers for me. I've had my stoma 40 years and I've managed it brilliantly but the development of an enterocutaneous fistula because of complications nearly broke me. I had many conversations with a lovely lady from Eakin who helped me source a bag that gave me a little bit of my life back!"

Lauraine

Read more about Lauraine's story on page

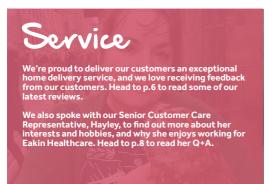
"I've had Crohn's disease since I was 12, I'm now closer than I'd like to 50! I've had a stoma for, I think, around 12 years now. So, I was in my 30s when I had the operation, and I was terribly worried about the whole affair. I hadn't really thought about the 'operational' aspect of prescriptions etc. but you guys, specifically Kerry at the Peterborough office for many, many years, made the process one I just didn't have to worry about; at all, ever!! I work in logistics so I understand how difficult it must be getting everything lined up to make your 'customers' lives easier; you must have one heck of a team to rely on!"

Paul

Read more about Paul's story on page 32

As always, we appreciate hearing your thoughts. Please keep the letters and e-mails coming.

What's inside issue 17?



Pages 6-16

We are delighted to once again to be able to share inspirational real-life stories from our customers. Head to page 25-34 to read Lauraine, Karen, and Paul's ostomy journeys and experiences, and how they have overcome hurdles along the way.

Pages 25-34

Product

We have a very exciting group product announcement to share with you... head to p.44 to find out how making a small change to your ostomy routine can have a big impact.

Pages 43-47

Events

In this issue we have updates from our 2nd annual Get Together event with our amazing ambassadors, head to p.18 to find out more.

We also share updates from recent events we have held and attended, and we share news of a new support group open in the Wirral area, head to p.23 to find out more.

Pages 18-23

Company news

We're excited to introduce to our readers, our new addition to our Community Stoma Care Nurse Team. Head to p.41 to meet Ivy and find out more.

Pages 41

Online

In this section we share updates from our ambassador, Rachel, who is raising money and awareness for a charity close to her heart on p.35, and you can find out more about our wonderful NEW podcast series. Check out p.37 to find out more and catch up on our latest episodes.

Catch up with the latest blogs from our ambassadors, covering topics like travel, complications with IBD and embracing stoma life, there's plenty for you to enjoy on p. 38.

Pages 35-39

Read our latest reviews





We're proud to deliver our customers a reliable, friendly, and supportive home delivery service. It means the world to us to hear what our service means to you, and your feedback helps us to continuously review and improve our services, so that we can ensure we are offering you the best service possible.

Read below some of our recent reviews:

"I have recently moved over to Respond after 10 years of dealing with ordering prescriptions from my GP, leaving it to the Pharmacy for ordering etc on my own. Trying to hold down a full-time job working various shift patterns, including night shift I found it frustrating and hard. Then I found Respond. I am so glad I made the move, simple easy to follow process, order online, choose the products you require and at the click of a button they arrive without delay. No running back and forth to pharmacy chasing missing products for weeks later. Any issues with your order Respond will contact you and advise and update, nothing is a problem for them. I only wish I had known about this service before now. 1st class outstanding service and the best people to deal with, they are always friendly, helpful and can never do enough. Thank you all at Respond. "

Simon

Would you like to leave us a review? Scan the QR code below or head to

www.healthcaredeliveryreviews.co.uk/









"Respond is an efficient and professional service. The customer advisors are always courteous, helpful, and meet my needs in a timely manner."

Barbara

"I have been using Respond for years their products (are) first class, service is extremely good, and the delivery system is first class as well".

Steven

"[Respond are] Always happy to help even when I need my order urgently. Such lovely understanding people who genuinely care about the customers".

Dawn

Not using Respond's home delivery service? Find out more about our award-winning service and why you should choose us on p.24



Psst... We've got something to tell you...

Our parent company Eakin Healthcare has been helping prevent leaks and skin irritation for ostomates for over 40 years with its range of **eakin**° seals.

We are excited to let you know these are now available to sample through Respond!

Using a seal as part of your **daily routine** is a **small** change...but it has a **big** impact.

Head to page 44 to find out more...





A Day in the Life of Hayley Morgan

Senior Customer Care Representative



1. How long have you been in your role?

I have worked for the company for 2 ½ years and have recently been promoted to Senior Customer Care Representative to better reflect my responsibilities as our team expands.

2. What does a day in the life of a Senior Customer Care Representative look like? Describe a typical day at work for you? I usually start each day by responding to sample requests for our group products. The sample requests can be anything from Pelican stoma

bags, to Respond's REFRESH 3 in 1 advanced adhesive remover. I really enjoy speaking to customers about their sample requests, as this allows me to make sure the requested samples are the most suitable products for them. It also allows me to fully understand any underlying problems customers may be experiencing. Typically, everyone I speak to has a story behind why they are looking to sample a product, and understanding this allows me to make sure that Loffer the best possible service. Once customers have tried our

products, it's great to stay in touch and find out how our samples worked for them, and to talk about their experience and get their feedback on our products.

3. What are your favourite things about your job?

I really love talking to customers and letting them know about our products and services. In particular, it's great to have a chat about things that customers might not be aware of. For example, if they are not already aware that they can choose to use Respond to dispense their appliances it's

Service

lovely to be able to share with them what our other customers sav about the service. It's always great to hear the reasons why customers love using Respond as we get such great feedback. I also love talking about our group products and finding solutions for customers. Most of my contact with customers is over the telephone. however I am fortunate in that I also get to speak to customers face-to-face when attending open days. It's always lovely to meet our customers in person, particularly after we have developed a relationship over the phone.

4. What makes you feel proud about working for Eakin Healthcare?

I can honestly say that we are a completely customer-focused company, and everyone in the team works so hard to deliver phenomenal levels of customer service. Our customers really are at the heart of our business, and our teams

go above and beyond for each and every customer.

5. Tell us about your biggest achievement in your current role to-

There is nothing more gratifying than helping a customer solve an ongoing issue that they have been experiencing or introducing them to a new product that gives them a better quality of life or makes them feel more secure and confident. I also enjoy letting customers know about the Respond prescription dispensing service, with its friendly and reliable service. It is always great to hear their feedback about Respond.

6. And, the biggest challenge?

Occasionally, finding the best solution for a customer can take several attempts, however I never give up and love the challenge of finding the right product for each individual.

7. What is the most important personal attribute that you bring to your job?

I love talking to people and problem-solving and this really helps me deliver the very best customer service.

8. What advice would you give to someone aspiring to get into your field of work?

To be a 'people person'. If they enjoy talking to people and building relationships it is definitely a role they would enjoy. It is important to have empathy and compassion, and to understand the very individual needs of an ostomate. It is also vital to keep abreast of new products that are coming to the market, to be able to offer the very best information and advice.

How would your friends describe you?

Funny, intelligent and (hopefully) kind.

10. What is your biggest passion or hobby outside work?

Watching films, reading and pub quizzes.

11. What does your perfect weekend look like?

Ideally, I would be on a city break with my husband. If I'm at home then a walk around Caerphilly Castle with my two dogs and a great film and a nice takeaway on the Saturday evening followed by a full roast

dinner on the Sunday (not cooked by me) and a relaxing afternoon planning my next holiday!

12. Which famous person would you most like to meet and what would you ask them?

As a fan of thriller and horror films I think I would have enjoyed meeting film director Alfred Hitchcock. He was a genius and an innovator: his films are classed as works of art even 60 years after they were made. I would ask him where his inspiration and vision came from and how he managed to translate his ideas to the screen so efficiently.

We would love to hear from you...

Here at Respond, family is everything to us and we think of you as part of our family. To help us continue to deliver our award-winning prescription dispensing service, we would love for you to leave us a review.

Simply scan the QR code or visit https://healthcaredeliveryreview.co.uk/review-form/ and help us to help others. #RespondFamily



Starter

Healthy pumpkin pancakes

Prep time: under 10 mins Cooking time: 30 mins Serves: 9 large or 27 mini pancakes

Ingredients:

- 200q plain flour
- ½ tsp baking powder
- 200ml milk
- 100g cooked pumpkin (or butternut squash), mashed
- 1 eqq, separated

pumpkin for butternut squash and still get the sweet flavours of these healthy pancakes. Use a non-stick pan to save using butter.



https://www.bbcgoodfood.com/recipes/healthy-pumpkin-pancakes

Method:

















STEP 1

Tip the flour into a bowl and add the baking powder. Measure the milk into a jug and stir in the pumpkin, followed by the egg yolk.

Make a well in the centre of the flour and gradually add the milk mixture until you have a lump-free batter. Alternatively, tip everything into a blender and whizz it.

STEP 3

Whisk the egg white until stiff, then fold it into the batter.

STEP 4

Heat a non-stick pan and cook 1 large or 3 small pancakes at a time (if making small pancakes, use 1 tbsp for each). Wait until lots of bubbles have risen to the top and the surface has begun to dry out before turning them over, but keep an eye on the base to make sure it doesn't get too brown. Repeat with the remaining mixture.



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and our friendly care teams will take care of the rest!

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Saving

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15 trees



DPD will provide all-electric delivery throughout 30 of the UK's largest towns and cities by the end of 2023.

DPD continues to invest in its all-electric delivery fleet and now has over 3,000 vehicles delivering 'green' throughout the UK.

Find out more at green.dpd.co.uk.





Meet the Family...

We spoke with our ambassador, Rachel, who has been using the Respond service for 6 years along with her little boy, Jake, to ask her what she thinks about our service and being an ambassador...

Tell us about yourself

Hi, my name's Rachel Allen. I'm a thirty four year-old mum from South Wales and I have a stoma due to Hirschsprung's disease. I have a seven-year-old little boy, Jake, who has the same condition as me - he has a stoma too. We're twinning and just living life to the full!

What do you think makes a great service?

Always being at the end of the phone. Being warm, friendly, and reliable.

How long have you been using the Respond service?

I've been using Respond since Jake was born in February 2016. The hospital where my little boy had his stoma recommended the service. and the relationship has blossomed from there. Four years after Jake's operation, I had my stoma and it was a no brainer to continue to use the Respond service, as we'd built a strong relationship. I knew I could trust Respond because of how wonderful they'd been to us, and we've never looked back.

What is it about the Respond service you like?

A lot of people I read about seem to have problems with the service they use, where they can wait for days wondering if products are going to arrive, but this just doesn't happen with Respond - they're really on it.

The service is very reliable. If I'm short of stock, or if we've had a month where Jake and I have used more bags than we were predicting, then it's just a quick phone call. I've had deliveries



within twenty four hours! You can't ask for better than that.

What three words would you use to describe Respond?

Warm, welcoming and reliable. I know that the Respond team are there for me and Jake and they always have been. For that very reason, whenever someone pops up on my social media feed asking for recommendations, I always recommend Respond. And I'll continue to shout their name from the rooftops! What I love is that the people answering incoming calls at Respond are so friendly and warm. You can feel their warmth over a phone call and I've felt that from the start...to the point that when I call Respond I need to remind myself I'm not ringing a mate, I'm ringing Respond.

What does it mean to you to be a part of the Respond ambassador programme and family?

Being part of the Respond ambassador programme feels like I have this great opportunity that I'm really thankful for. I just want to give back because the platform that Respond have created allows us to educate people and raise awareness.

It's all about education and getting that message out there that you're not alone - we are out there. By working with Respond, we're all supporting the ostomate community as best we can. To me, we do feel like family.

What would you say to someone who was looking to change their service?

Do it now. There's no reason why you cannot have the best – it is out there and it is Respond. You need to remember that you are going through something that not many people have to deal with in their lives and there's no reason why you shouldn't get the care and the customer service that you deserve. Please don't hesitate to join Respond.

Tell us three things we don't know about you?

Firstly, I'm a Family ambassador for Noah's Ark Children's Hospital Charity in Cardiff, South Wales. Our son's 13 operations have been carried out at Noah's Ark Children's Hospital, and they will continue to provide him with the care that he needs

Secondly, I am a trained teacher and am passionate about sharing what life is like as a parent ostomate, as well as being one myself, through my ambassador role, blogging, and planning meet ups for ostomates.

Thirdly, my celebrity crush is Jason Statham!



you can also get your continence supplies through Respond?

Millions of people are affected by urinary incontinence and if you, or someone you know, uses continence care products such as catheters, sheaths, and urinery leg bags, then Respond can also dispense these products on prescription.

Many Respond customers take advantage of being able to receive all their stoma care and continence care products from us in one delivery. This saves them having to deal with two different prescriptions.

If you use continence care products, just let our friendly team know the next time you place your order and they will take care of everything. If you have a friend or family member that would benefit from having all of their continence products dispensed though our award-winning prescription dispensing service, then why not recommend Respond today?

Get in touch today to order your continence supplies

Phone: 0800 220 300 / 0800 028 6848 (N.Ireland)

Online: respond.co.uk

Email: hello@respond.co.uk



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The Get **Together 2023**

Another year, another Get Together...

We were very grateful to have held our second Get Together this year where we brought together our amazing and inspirational group of ambassadors to help us raise awareness of those living with a stoma, and to celebrate the incredible achievements they've helped us over the past year.

From making meaningful connections and having inspiring conversations over a private dinner, to watching them feel empowered and confident during a photoshoot - we wanted to say a BIG thank you to all our wonderful ambassadors for making the two days a truly special and memorable experience. Here's to next year!





A BIG thank you to all of our ambassadors - Rachel, Mohammad, Louise, Chris, Summer, Phillipa, Ant, Angelina and Charlotte – for an amazing two days!

The Get Together 2023

Here's what our ambassadors said:

"The Get Together 2023 was amazing this year! It felt so good to reunite with fellow ostomates who we haven't seen in a long time and all of the Respond and Pelican team as well as some new faces! It's a fantastic few days and to be able to be a part of it and see everyone in person is so lovely! It's like seeing your distant family again who are all so inspiring!"

Phillipa

"The two days at The Get Together 2023 were an incredible experience, fostering meaningful connections and inspiring conversations. It was a truly memorable event that left me feeling energised, connected and inspired."

Angelina

"The Get Together in Cardiff was a chance to spend two days with fellow ambassadors, and a room full of ostomates who get it. Priceless!"

Keith

"The Get Together 2023 was a beautiful moment in time where we could just be, with people who just get it. The relationships formed with my fellow ambassadors is something I will always treasure. I thank Pelican and Respond for bringing us together and their continued support."

Rachel

"Simply the greatest meet up ever! Last year I missed out on my first meet up with everyone, so to FINALLY be able to meet all of the team, the ambassadors, have a laugh, share stories and be around so many inspirational people, made The Get Together a highlight of my year!"

Ant

"The Get Together was SO wonderful! I adored every single minute and felt so lucky to be part of the Pelican, Eakin & Respond Family. I spent two days surrounded by amazing and inspiring individuals and came away with a huge smile"

Charlotte





Recent events

In May, our Community Stoma Nurse, Helen, attended the Urostomy Association afternoon tea in Belfast, to celebrate their 50th year since launching in the UK. Whilst they actually turned 50 in 2022, they were busy planning and attending their celebratory events throughout the year, so Donna Watson, Urostomy Association volunteer for Northern Ireland, and Helen, were glad to finally be able to get together to celebrate in Belfast.

Donna presented Helen with a beautiful bouquet of flowers for all her help at the meetings.



Shropshire & North Wales Urostomy Association visit to head office

In April we had the pleasure of hosting the Shropshire and North Wales Urostomy Association group to our head office in Cardiff, where they took part in an ideation session and factory tour.

Toni Haines, secretary of the Shropshire, Wales and The Marches UA branch, shared her account of the day with us:

Once the Covid lockdowns had finished and our branch of the Urostomy Association, Shropshire, Wales & the Marches, tentatively began holding meetings again, albeit with social distancing and open doors and windows, we started to think about events and visits. As Secretary of the branch, I approached Natalie Smith, Pelican representative for the middle part of our huge branch, to ask if we could arrange for South Wales members to visit the Pelican factory, in Cardiff.

Natalie, as always, rose to the challenge and suggested that instead of February, we choose April, when the weather would be less likely to cause problems, so it was agreed that a visit would take place on Thursday 6th April. In actual fact, it was just as well that we chose April, because we had been forced to cancel a branch meeting in Shrewsbury in March because of heavy snowstorms!



The Deputy Chairman of the branch, Graham Catherall, said that he would also like to attend, along with his wife Gwen. We drove down on Wednesday and Graham and Gwen came by train. Graham is in a self-propelled wheelchair, so that train travel, when all goes well, is better than driving long distances. We stayed at a beautiful hotel, New House Country Hotel, on the Cardiff side of Caerphilly Mountain. Don and I were brought up in the other side of Caerphilly, so it was quite nostalgic for us.

The next morning Natalie took Graham and Gwen to the factory, Natalie's car being big enough to hold Graham's lightweight wheelchair and luggage.

The rest of the South Wales members were already at the factory, including Andy Chartres, who is on our branch committee, and Ian Hawthorn and his wife. Unfortunately, Brian Williams and his wife couldn't make it, car problems! Another member, Margaret Wilcox, couldn't make it as she was unwell.

Graham Catherall is still a professional photographer, although now retired, and he was snapping away whilst we toured the factory, we weren't very keen, because the outfits we were required to wear were not exactly "haute couture"! However, as usual it was really interesting to see perfect stoma appliances being manufactured by the incredibly complex machines and to realise how fortunate we ostomates are to receive this kind of care.

Afterwards we had a nice lunch and then some of us went individually with members of Eakin Healthcare's Research and Development team to give what we hoped was constructive feedback of new ostomy products that they will be bringing out in the near future. I have the experience of having been a urostomate for 30 years and Graham has been one since he was a baby, with many extra challenges, being in a wheelchair - whilst the others in our group were relative newbies. However, each of us was able to give the insight of someone who uses a urostomy pouch every day, albeit from different perspectives, and hopefully the Pelican team found our comments useful.

This was a very interesting and worthwhile visit to the Pelican factory, so thank you to all involved for making our visit so memorable.

Are you a member of a support group or association and would like to share any upcoming events with our readers? Get in touch today at marketing@respond.co.uk

ASCN 2023

Along with our colleagues in Pelican and Eakin, Respond will be exhibiting at the Association of Stoma Care Nurses UK (ASCN UK) Annual Conference in Brighton from the 8th-10th October. We have been busy preparing for the conference, where we will be able to meet with stoma nurses across the country, giving us the opportunity to showcase our service and products, at the biggest conference of its kind in the UK. We look forward to meeting and networking with fellow industry colleagues, charities, volunteer groups,



and the nurses in attendance – including our own Community Stoma Nurses!

The theme of this year's conference is "Making Waves and Influencing Practice". The programme is filled with insightful keynote speakers and presenters, discussing a range of topics that will enhance the practice of those involved in delivering stoma health care. We are delighted that educational posters produced by our Respond Community Stoma Nurses have been selected to be displayed at the conference!



NEW support group in Wirral

We are delighted to share with our readers a new support group being set up in the Wirral area. Group leader, Jo Woods, has the following to share:

"The support group runs once a month, on the 1st Tuesday of the month at Dining 107 in Heswall from 10am-12pm. Open for all pre or post-stoma surgery, even after a reversal, if you'd like to come along to chat and share stories and advice.

It is £4 for unlimited tea and coffee if you would like, and I always bring cake – usually homemade!

A very relaxed and friendly group, any questions or if you'd like to come along, please message me (Jo Woods) on 07956 216218."



Why choose Respond?

We offer a reliable and convenient service putting you first and meeting all your needs, not just your prescription requirements.



Confidence

No matter which products you use, we can dispense them



Discretion

Discreet and unbranded packaging and delivery



Dispensing your prescription

Making prescription ordering easy with local care centres across the country



No queuing

We will call you in the comfort of your own home. Hassle free!



Global Assistance

To help you with emergency stoma supplies when travelling away from home, giving you peace of mind



Customisation

We machine cut your bags to the required size at our own premises, ensuring a 100% quality inspection



Complimenting items

Dry wipes and disposable bags are provided as standard, with a wide range of other support items available to you



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We cover a wide range of topics such as ask our nurse, sex and intimacy and more



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My life story By Lauraine Clarke

We recently spoke with Respond customer, Lauraine, who shared with us her incredible ostomy story and her inspiration for writing her own book, discussing the complications she has encountered. Take a read below.

I first experienced bowel problems in 1985 when I was in my 20s. Unrelenting bloody diahorrea, vicious cramps, accompanied by numerous intra intestinal problems like abscesses and joint problems, plagued my days and denied me any kind of normal life. After numerous hospital stays, I was diagnosed with Crohn's Colitis. In those days the only treatment was Prednisolone and Sulfasalazine, both of which I tried but nothing really worked. After several years I had an ileostomy which restored my health within weeks. I had a two-year-old daughter and a husband in the military – life was so much better with a stoma! In those days, with no internet I was pretty much alone with this though and in any event 'bums and poo' were the unmentionables plus most people had never heard of a stoma!

After a few years I developed abdominal problems again and was diagnosed with severe endometriosis which meant another 20 years of surgical interventions and procedures. I continued to work full time, but it



became a struggle as I got older. My faithful stoma however never let me down and my bowel health remained good.

In 2015 I had a hysterectomy, and the plan was to remove my rectum at the same time. Disaster struck as my small bowel was perforated and I was plunged into the dark world of rare surgical complications. I spent months in hospital being vein fed in the hope my bowel would heal. It didn't heal and I ended up with an enterocutaneous fistula which is basically an abnormal connection between my small bowel and skin. I had several openings on my abdomen all of which acted like mini stomas and leaked poo. It was a living hell and worse was to come.

Eight years on I still have the fistulae and now wear two bags and a dressing. This is a permanent complication as to fix me is too

Real life

dangerous. It took me many years to find a wound bag that didn't leak and Eakin and Respond have been life savers throughout this torrid journey. At one point I had to wear three bags, TWO for the fistulae and one for my long standing stoma. I was so depressed! I had many conversations with Eakin, and they suggested their Eakin wound bag. This changed my life, and I was able to go out for the first time in a long time. That gave me a massive boost. The staff at Respond have been equally amazing, nothing is too much trouble and I feel they always go the extra mile. As I have memory problems following sepsis, they phone me every month to check what I need, the service is second to none.

A few years back I decided to write a book about my experience. Surgical complications are rare but that doesn't mean they never happen as my story shows. My book 'Sharp Scratch' enters this dark side of surgery and showed how I eventually reached a point of acceptance, although difficult at times. My mental health has plummeted at times, and I have been diagnosed with PTSD and anxiety which is hardly surprising.

I still have the original stoma that I had 40 years ago. My small bowel continues to nourish me, and I can eat and drink now, for which I am very grateful. The bags are difficult as the fistulae are recessed into my abdominal creases, so getting them to stick is challenging but I've worked out a routine that works ok.

I'm 62 now and life is good again.
I'm grateful for every day I feel well
but always live in fear of the fistulae
causing problems as I know how
dangerous having more surgery is.
I'm trying to focus on the positives of
which there are many - my stoma is
my saviour and whilst that continues
to work, I hope I'll be ok.

Thank you for reading, Lauraine x

To find out more about Lauraine's ostomy journey and her book head to her Facebook page "Sharp Scratch". Lauraine's book discusses surgical complications and the devastating impact they have had, but also how she has been able to reach a point of acceptance. The book is being published by a small publishing house in Wales and is available to purchase on Amazon (QR code below). Check it out today!





Swapping the hospital gown for a pageant crown By Karen Bucknall

Karen bravely opens up about her cancer diagnosis and journey, and talks openly about the feelings of PTSD and survivors quilt, and how stepping into pageantry and modelling have helped her confidence in living life to the full.

Hi! I'm Karen, 52, from Cheltenham, Gloucestershire. I've had my colostomy since 2019 after my bowel cancer surgery. My colostomy bag is called Brenda, after my late Aunty Brenda who wore a colostomy bag for many years.

I reached out to Respond to share my story with fellow Connect readers, to hopefully help and support other cancer patients and survivors.

In April 2019, I was diagnosed with stage 3 bowel cancer. I had radiotherapy, chemotherapy, and surgery, but unfortunately, the cancer spread into nearby lymph nodes and vagina. I rang the 'All Clear Bell' in July 2020, although I still have cancer in my rectum that they couldn't remove, and I have cancer markings on my liver. I wear a colostomy bag, 'my bag for life, that saved my life', and I also have a Barbie Butt (sewn up bum). And just like Barbie, I love wearing hot pink and living my best life ever. Dream it, believe it, and achieve it. You can be anything you want to be, Barbie's motto and mine too.



In addition to this I had a hysterectomy after having bowel cancer, cysts, and a benign tumour on my uterus, which when removed was equivalent to a five month foetus. I also have a benign brain tumour, an Acoustic Neuroma, with constant brain pressure, which affects my mobility and balance and problems with hearing.

May 2023 marked my eight year journey of living with benign and cancerous tumours. When I had my hysterectomy in May 2015, I thought that was the worst thing that I could ever go through, let alone getting a benign brain tumour and bowel cancer. which has resulted in having a stoma and wearing a colostomy bag.

I would like to share my Pageant Queen, and plus size model story with you all, to inspire and empower other



women and girls that are going through bowel cancer, that you are not defined by having bowel cancer and wearing a colostomy bag. You are defined by being the amazing you and going out there and kicking bowel cancer in the bum! Having bowel cancer isn't the end, it's just the beginning of an exciting new chapter in your life. With many adventures, experiences, fun, travels, and meeting the most amazing people along the way.

By doing pageants and plus size modelling, it has helped me with my self-esteem, self-confidence, and more positive body image. No longer do I want to hide my colostomy bag and stomach surgery scars. I now want to tell the whole world that it's okay to wear a stoma bag, and it's okay to wear a bikini, or tankini and proudly show your bag to the world. I am no longer ashamed and embarrassed of my "Barbie Butt", because I can relate it to Barbie. As a girl, I had Barbie and Sindy dolls. With their clothes, accessories,

shoes, the house, the horse, the camper van, the sports convertible car. To me, my post bowel cancer and benign brain tumour life is now like living out the fashion dolls' glamorous lives.

Taking part in pageants is wonderful because I've met so many lovely women and girls along the way, many of them are living with invisible illnesses, hidden disabilities, or disabilities. It is a friendship network where we encourage and support one another, and a national / international sisterhood.

There are also other girls that have had hysterectomies like me, and some were even younger than my 44 years when I had my hysterectomy. Whereas other girls/ women like me have had cancer, whether breast cancer, ovarian cancer, brain cancer or bowel cancer. It doesn't make me feel so alone in the world, because I now know that other finalists in pageant-land and in modelling who live with life threatening and changing medical conditions, and are becoming pageant queens and models too.

I never thought for one moment that I would go into pageants or plus size modelling, it just happened by winning competitions and being in the right place at the right time. I enjoy doing it very much, it's my passion and gives me a purpose. I like the fact that in pageantland and in modelling it is becoming more inclusive and diverse, but it still has a long way to go but slowly getting better. It is not just the dress and the heels, the winning and the old fashioned 1970's

Real life

Miss World ideology of vital statistics and world peace message. Today's modern pageants are for everyone, it's about campaigning for your cause, using your voice, doing local community work, and charity fundraising. The dress and the run way walk are just a small percentage of the overall scores. The person, their passion to do good, their aim and objectives and purpose in life, alongside their personality and their good community and charity fundraising work is considered and scored on too.

Therefore, I am the first Pageant Queen and size plus model, bowel cancer survivor, who has a stoma and wears a colostomy bag with a Barbie Butt, who is also living with a benign brain tumour and post hysterectomy, not in the UK, but in the world. I am very proud of all my achievements because determination and sheer hard work really paid off. However, I wish more women and girls that have or had cancer, tumours, or hysterectomies, had the confidence to go into pageantry or modelling, because we are a small minority, marginalized and underrepresented.

When my consultant and surgeon told me after a few days of my stoma surgery that the cancer had gone into my vagina and lymph nodes, I was absolutely mortified, gob smacked and I burst out crying. I felt so ashamed and embarrassed and so alone in the world. Having been diagnosed with bowel cancer and vagina cancer, I felt very dirty, demoralised, depressed, and degraded as a human being. I felt a bit of a freak, a medical

mystery, and a burden on the NHS. Often thinking and crying in private. What did I ever do to deserve this?

Now I just want to break down barriers, shatter the glass ceiling, and speak up about "embarrassing cancers". That there is nothing to be ashamed or embarrassed about having rectum cancer or vagina cancer. I want to reduce the shame and stigma linked to having these cancers. When it affects anything linked to poo, blood and wee, or cancer of the sexual or reproduction organs. My bladder has become very weak after the hysterectomy, bowel cancer and vagina cancer. Sometimes I feel like I should buy shares in Tena Lady. Vagina cancer is horrible because it does leave you slightly deformed from the surgery, and feeling ashamed, embarrassed, and undesirable as a woman.

However, living with a stoma hole, surgical scars, my Barbie Butt, and wearing a colostomy bag, I just accept it, embrace it, and value it, and give thanks that I'm still alive. I'm living my best life ever, and making every day count, because every day is a precious gift.

What isn't often talked about is posttraumatic stress disorder, PTSD, and survivor's quilt. I am nearly 53 years of age, I have never met Mr. Right, and I never had children/ grandchildren. When I had my hysterectomy, I was 44 years of age, and to some extent my love, marriage and babies dreams came to a very abrupt end. I sometimes feel guilty, thinking why am I still alive, when others



lose their family. Why do married people, people with children and grandchildren, get cancer or brain tumours and are taken far too soon, and I'm still here? Whilst I am still going strong, I still live with a lot of post cancer pain, with more poo disasters than I care to mention, but somehow, I am still here and always no matter how bad or good, I get through the day and smile.

I hope this gives you an insight into my story. It's important for me to share my story by inspiring and empowering others that you can do anything when you are a post cancer survivor, because basically you've been given a second chance. There is always the fear that my cancer will come back again. My benign brain tumour has grown again, so I do live in constant fear of my rectum cancer growing and cancer spreading around my body again, but if/ when it does it won't be so bad the second time around because I will know what to expect and be able to deal with it positively. Because cancer, a benign brain tumour, and

hysterectomy have made me braver and bolder and more beautiful as a person. To think how much my world has changed since bowel cancer and wearing a colostomy bag. It's all for the best.

Thank you all for your attention and time, Karenx

Keep up to date with Karen by checking out her Facebook page, facebook.com/KarenEBucknall where she shares her honest and open account of living with bowel cancer, wearing a colostomy bag, and living with a benign brain tumor.

E-ngage with us!

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

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

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

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

Why not share your news on Instagram and Twitter: a Colostomy UK



My ostomy story By Paul Haines

We recently spoke with ostomate and Respond service user, Paul Haines, 48 from Burt St Edmunds, Suffolk, who has had Crohn's Disease for 36 years and wanted to share with us his experience from diagnosis to living with a stoma.

I was 12 years old when I was finally diagnosed with Crohn's after nearly 2 years of experiencing many different symptoms. Back in the 1980s the diagnostics for Crohn's were nothing like they are now, and I was tested for all kinds of nasties; luckily, depending on your viewpoint I suppose, I was confirmed to have Crohn's Disease.

I was happy that the diagnosis had been made but was slightly confused as I believed, incorrectly obviously, that it was only older people who suffered with the disease. I was placed on high doses of prednisolone which helped although I now know it purely masked the symptoms and came with its own problems. Incidentally, I was placed on such a high dose of steroids that they stunted my growth, so I'm the same height now, in my late 40s as I was when I was 12. This, obviously, has had its own difficulties!



I've always been positive about my illness; I've fought it over the last 35 years, and I've never let it define me. It's nobody's fault, it can't be helped, and I've made sure that whatever I've had to deal with, I'd deal with it head on. That being said, some of my work colleagues and friends see me as the fun, positive and confident man that I portray I am but sometimes it's just a struggle to get up in the morning, but I've made that my problem and no-one else's I suppose?

Over the last 35 years, I've had numerous surgeries for resections and finally begged my wonderful surgeon for an ileostomy around 13 years ago. Even then, being a man in his 30s with a 'bag' was taboo and there was loads of stigma and lack of knowledge around the entire subject. It turns out that I should've made the decision years before; that operation, which saw me at my absolute lowest ebb, changed my life. I remember my wife and kids

Real life



wanted to go to the coast to celebrate my then ffiancée's birthday, but I was curled up on the floor in our kitchen in agony. I told them to go without me. I wasn't having that kind of feeling anymore and I called my surgeon the very next day.

So, it's been 13 years of living with an ileostomy, I'm active, fit, strong, I haven't had a day off work in the last 8 years, it was the best decision I ever made (after marrying my wife, obviously!). Yes, there are annoyances and things that are challenging, but there are also benefits, above and beyond not being in excruciating pain throughout the day and night or needing the loo 30 / 40 times a day, I can now go to the loo whenever I need to!

The world still needs educating, although things are so much better with 'invisible illness' signs on accessible toilet facilities and numerous fellow 'Crohnies' posting their experiences on social media. But

I still come across tutting and people giving me strange looks when I use 'disabled facilities'. I have been known to confront these people by saying as much as it is that you can't tell how ignorant someone is by looking at them, it's the same for being able to tell if someone has disabilities. That comment does leave some people scratching their heads!

My wife is a keen cyclist and every year, we take a week off work and cycle around the coast of North Norfolk and Suffolk. After the numerous operations I've had, I've barely any small bowel left, and no colon left at all. This makes it very difficult taking on fluids as I'm generally always technically dehydrated so cycling 180 miles in the hottest summer we've ever had last year was another challenge, but one I faced and managed. It has to be said, it was the draw of the plentiful coastal pubs that drove me up those hills!

My friends and family say I'm an inspiration, I don't agree, I'm just making the best of what I have. In my opinion, too many people look for a reason not to do things. I try to be the opposite, why shouldn't I do these things is my ethos. I'm forever thankful for the consultants. surgeons and nurses that looked after me throughout my illness. I'm lucky enough to be friends with some of them still, they are the real heroes in my life, those, and the fantastic teams at Respond Healthcare.

I'm an organised kind of chap, I was a Project Manager for many years, and I



never knew if I was organised because I was a Project Manager or whether I was a Project Manager because I was organised! This meant that learning about managing my stoma and making sure I had everything I needed at all times was quite a concern for me. We've all experienced ever changing encounters with the NHS and I was worried about ending up without having what I needed available for the day-to-day management of my ileostomy; I need not have worried! The teams I have dealt with at Respond have been perhaps the most reliable team of individuals I've ever dealt with. This has been constant over the last 13 years. I can honestly say I have never had one bad experience of dealing with these guys. They are friendly, knowledgeable, helpful and above all, understanding. They know what we're all going through, and they know that worrying about things isn't good for us and they're there to make our lives as straightforward as possible. I manage my supplies how I like to and place larger orders but less frequently, but they allow me to do things

which work for me. As part of my job, I run a Customer Service centre, they don't know it but my 'go to' example of how to run a Customer Service operation is the Respond team. They are a team of real people, who can and do make a difference and offer a truly amazing service. Behind the scenes there must also be an equally as amazing warehousing and logistics operation, so I say thank-you to those guys too. If there's one thing that I just don't have to worry about, it's being without things I need from Respond; they are real life savers.

Now, I could go on and on about my experiences, but my wife says I talk too much so I'll leave it here and have one thing to say and that's thank-you.



Thank you for reading, Paul

We recently spoke with our ambassador, Rachel, who is taking part in the Cardiff Half Marathon this October, to help raise awareness and support for a charity close to her heart:



This October will be the second year I run the Cardiff Half Marathon for Noah's Ark Children's Hospital Charity in Wales. My mission is to raise funds and awareness for the charity which funds vital equipment, therapies, and resources to support the sick children of Wales and beyond. They have supported my little ostomate Jake since birth and will continue to do so until he is 18.

It is only through funds raised that Jake and children alike can get the vital resources they need to reach adulthood and have the best quality of life possible.

Anything you can give to donate and support my cause would be greatly appreciated!

If you'd like to make a donation scan the QR code or head to www.justgiving.com/fundraising/rachel-allen57



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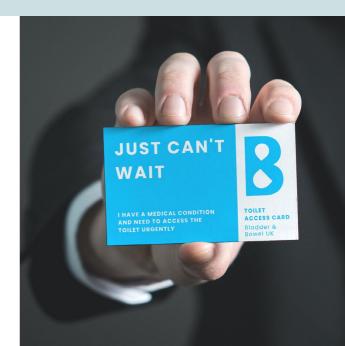
Although access is not guaranteed, the cards are widely accepted and acknowledged.



www.bbuk.org.uk













Beyond the Pouch with Rachel & Louise

Brought to you by Pelican, Respond and Eakin Healthcare, Beyond the Pouch is a podcast that follows hosts, Rachel & Louise, as they dive into the world of ostomy through open and honest conversations, including the lives of many inspirational ostomates, so you can get to know them – Beyond the Pouch.

Watch & listen now







Latest blogs...

Our digital team has been busy collaborating with our amazing Brand Ambassadors once again, to bring you insightful blogs covering a wide range of topics over on our blog section of the website. We've picked a few for you to read in this issue. Take a look...

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Travelling with an ostomy

by Keith

How do you manage your stoma in summer? From change in output to staying hydrated, (@keiththom2014) shares his experience managing his stoma in summertime.

We also have lots of great travel tips over on our website, scan the QR to the right to read all our travel advice blogs!

Scan the QR code to the right or visit www.respond.co.uk/2023/06/28/travelling-with-an-ostomy-by-keith/ to read.





Embracing life's journey: My battle with colon cancer

by Mohammad

In this blog, Mohammed

(@colon_cancer_and_me)

opens up about his battle with colon

cancer and living with a stoma.

Scan the QR code to the left or visit www.respond.co.uk/2023/07/06/ embracing-lifes-journey-my-battle-with-colon-cancer-by-mohammad/ to read.

Latest blogs...



What are the extraintestinal manifestations of IBD?

by Amy

There are many effects that IBD has on the body and many of those are outside of the intestines (hence "extraintestinal"). Read Amy's (@ibdwarriorprincess) blog to find out more.

Scan the QR code to the left with your smartphone or visit

www.respond.co.uk/2023/07/24/what-arethe-extraintestinal-manifestations-of-ibd-byamy/ to read.

We hope you've enjoyed reading our Brand Ambassadors' blogs.

More are available to read on our websites respond.co.uk/blog and
pelicanhealthcare.co.uk/ostomate-blog.

Do you have a question for one of our ambassadors or would you like to tell us about your story or experience? If so, please send an email to

marketing@respond.co.uk

and a member of our fantastic digital team will contact you!





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www.urostomyassociation.org.uk



Introducing

We are pleased to introduce to our readers another new member to our Community Stoma Nurse team, Ivy!

lvy began her nursing in Africa, Ghana in 1986 where she trained to become a registered nurse, midwife, and a public health nurse. In 2002 she moved to United Kingdom and has worked as a RGN in hospitals, care homes, district nursing and has been a bladder and specialist nurse for 5 years.

"I pride myself with putting my patients' needs first and I ensure I treat them as individuals and provide them with the highest quality care".

Available upon request covering the Preston area providing impartial advice on stoma care and products, Ivy is here to support you at home alongside your team at the hospital.

For more information or to speak to lvy please email hello@respond.co.uk

Main

Creamy pork & pear cassoulet

Prep time: under 10 mins Cooking time: 50 mins Serves: 4

Nutritional

This recipe contains garlic and onion, which are trigger foods for those with an ileostomy and colostomy. Please be mindful of your personal tolerance to both ingredients, you may

Ingredients:

- 2 tbsp vegetable oil
- 400g pork loin steak, cut into strips
- · 2 medium onions, sliced
- 2 garlic cloves, crushed
- small pack sage leaves, chopped
- 2 tbsp plain flour
- 500ml bottle apple or pear cider
- 2 medium pears, cored and each cut into 8 slices
- 100ml double cream
- crusty bread, to serve



Recipe card

https://www.bbcgoodfood.com/recipes/creamy-pork-pear-cassoulet

Method:



















STEP 1

Heat half the oil in a medium saucepan or flameproof casserole dish over a high heat. Season the pork and fry for 3-4 mins, then transfer to a plate. Reduce the heat to medium and add the remaining oil and onion. Soften for 8 mins, then add the garlic and fry for another 2 mins.

STEP 2

Add the sage and flour, stir and cook for 1 min. Increase the heat, then pour in the cider and bubble for 4 mins. Return the pork and juices to the pan, season, then reduce to a simmer and cover. Cook for 10 mins.

STEP 3

Add the pear slices, stir and cook for another 10 mins. Stir through the cream, season, then divide between bowls and serve with crusty bread.





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eakin® seals through Respond

We are excited to announce that you can now request samples of **eakin® seals** through Respond! We know that not all our customers will be aware of seals and the benefits they may bring to your ostomy routine, so we wanted to share with you some more information about them, their benefits, and when you may want to use one.

Take a read below and head to the end of the article to find out more.

What is a seal?

A seal, also known as a washer or barrier ring, is a ring-shaped appliance that can be applied under your baseplate to provide an extra layer of security. Its aim is to prevent output from coming into contact with the skin around your stoma.

Why might you use a seal?

Some of the most common problems ostomates tell us about are leakages and skin irritation. If you are finding your output is getting under your baseplate, your baseplate is wearing away very quickly, or your skin is becoming itchy, sore, irritated, or even broken, then a seal may be the solution you need to prevent this from occurring.

Below are some other challenges that you may experience with your stoma, where a seal could be a suitable solution for you:

- Stoma changing shape or size
- · Adhesion issues due to irritated skin
- Watery or loose output
- Uneven skin around your stoma
 creases or folds
- Stoma being flush to the skin or retracted

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there are seals
for all stoma
shapes...try
one today



- A parastomal hernia, which may cause leaks due to the size, or the surrounding skin may become stretched and fragile, needing some extra protection
- Incorrect stoma bag choice or baseplate sizing
- Frequently changing your stoma bag
- Granulomas red bumps around the stoma
- Anxiety or fear of leaks occurring, needing some extra confidence with your ostomy products

How can I choose which seal is best for me?

With so much choice it can be difficult to decide which seal is the right one for you. We suggest thinking about the following three things when choosing a seal:

1. Why do you need a seal?

Think about the reason you are trying a seal — if it is due to leakage or trying to extend wear time, then choosing a more absorbent seal is important to help absorb output.

If it is to create a more secure fit, then a more mouldable seal that is flexible and easy to manoeuvre into the shape and size you need for your stoma is important.

If you are wearing a convex bag and your stoma is closer to your skin level, then you may wish to consider a thin seal.

2. Your lifestyle

Thinking about the things you like to do may help in choosing the right seal for you. If you are very active, choosing a flexible seal that flexes with your movements and helps with pouch adhesion would be an important consideration.

3. Your skin

Thinking about your skin is also an important factor when choosing the correct seal. Does your skin have lots of dips or fine lines that the seal needs to be able to mould into? You might want to consider a mouldable or slightly larger seal to help fill in those dips and creases to create a more secure fit of your bag.

Or do you have sensitive skin? If so, you may wish to consider choosing a seal with no additional additives.





We hope you have found this article a useful overview of seals. Scan the QR code above or visit respond.co.uk/eakin- seals to find out more and to sample eakin® seals today!

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specialists in stoma

Dessert

Vegan ginger loaf cake

Prep time: 15 mins Cook: 45-50 mins **Serves: 8-10**

Ingredients:

- 100ml vegetable oil, plus extra for the tin
- 275q self-raising flour
- 150g dark muscovado sugar
- 1 tsp baking powder
- 1 tbsp ground ginger
- 50q treacle
- 50g stem ginger from a jar, finely grated, plus 1 tsp of the ginger syrup
- 150g icing sugar
- 1/2 lemon, juiced
- 4 crystallised stem ginger pieces, sliced

https://www.bbcgoodfood.com/recipes/vegan-ginger-loaf-cake

Method:

















STEP 1

Heat the oven to 200C/180C fan/gas 6. Oil a 900g loaf tin (ours was 19 x 9 x 6cm) and line with a long strip of baking parchment. Mix the flour, muscovado sugar, baking powder and ground ginger together in a large bowl. Tip in the oil, treacle, grated stem ginger and 170ml cold water, then beat together until smooth using a wooden spoon.

STEP 2

Pour the cake mixture into the prepared tin and bake in the centre of the oven for 45-50 mins until a skewer inserted into the middle comes out clean. Leave to cool in the tin for 5 mins, then transfer to a wire rack to cool fully.

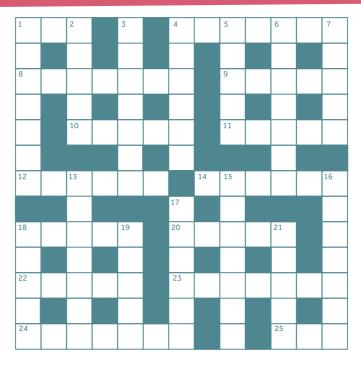
STEP 3

Sieve the icing sugar into a bowl, add the ginger syrup and mix in just enough lemon juice to make a thick, pourable icing that can coat the back of a spoon. Put the cake on a plate or stand, remove the parchment and drizzle over the icing. Immediately scatter over the stem ginger. Cut the cake into thick slices to serve.



Puzzle page

CATCH WORDS



Across

- 1. The Ryder (3)
- 4. ____ is the spice of life (7)
- 8. Louisiana, the ____ State (7)
- 9. ___ light show (5)
- 10. Lesser of two ____ (5)
- 11. The of time (5)
- 12. ____ said than done (6)
- 14. ___ and liabilities (6)
- 18. Great minds think (5)
- 20. A drop in the (5)
- 22. ___ on the cake (5)
- 23. Caught ____ (7)
- 24. Short ____ (7)
- 25. Original ____ (3)

Down

- 1. A audience (7)
- 2. A finger on the ____ (5)
- 3. It is better to give than ____(7)
- 4. ____ into thin air (6)
- 5. ___ and regulations (5)
- 6. Time is of the (7)
- 7. Inches, feet and ____ (5)
- 13. Plain ____ (7)
- 15. Church and ____ (7)
- 16. Riding (7)
- 17. ___ a phrase (6)
- 18. ____, the ram (5)
- 19. Pieces of ____ (5)
- 21. Hard as ____ (5)

Know someone living with Crohn's Disease or Ulcerative Colitis









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SUPPORT - EDUCATION - ADVOCACY

Puzzle page CATCH WORDS

Answers

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Useful contacts

Colostomy UK

100 Berkshire Place, Winnersh, Wokingham RG41 5RD

T: +44 (0)118 939 1537 Helpline 0800 328 4257 E: info@colostomyuk.org colostomyuk.org

Ileostomy Association

Danehurst Court 35 - 37 West Street Rochford Essex SS4 1BE

Freephone: 0800 018 4724

T: 01702 549859 E: info@iasupport.org www.iasupport.org

Urostomy Association

2 Tyne Place Mickleton Chipping Campden Glouestershire GL55 6UG

T: 01386 430 140

E: info@urostomyassociation.org.uk www.urostomyassociation.org.uk

Crohns and Colitis UK

1 Bishops Square (Helios Court) Hatfield Business Park Hatfield Hertfordshire AL10 9NE

T: 0300 222 5700 www.crohnsandcolitis.org.uk

Macmillan Cancer

87-90 Albert Embankment London SE1 7UQ

Freephone: 0808 808 00 00 www.macmillan.org.uk

community.macmillan.org.uk/cancer_ experiences/ileostomy_and_colostomy_discussions/

Mind

15-19 Broadway Stratford London E15 4BQ

T 0300 23 3393 E info@mind.org.uk Text: 86463 www.mind.org.uk

contact us

0800 220 300 0800 028 6848 (Northern Ireland)



Cardiff

Greypoint Cardiff Business Park Cardiff CF14 5WF

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London

23 Heritage Avenue London NW9 5XY

Direct 0208 166 4593 Fax 0203 051 2412 8:00am to 5:00pm Monday to Friday Closed Saturday

Peterborough

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Direct 01733 348 883 Fax 01733 806 515 8:30am to 5:30pm Monday to Friday 8:30am to 12:30pm Saturday

Ferndown

530 Wimborne Road East Ferndown Dorset BH22 9NG

Direct 01202 890782 Fax 01202 031708 8:30am to 5:30pm Monday to Friday Closed Saturday

Manchester

2 Victoria Avenue East Manchester M9 6HB

Direct 0161 702 3380 Fax 0161 820 4510 8:00am to 5:00pm Monday to Friday Closed Saturday

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