

A HIGHLY COMMENDED MAGAZINE

# Connect

AUTUMN  
ISSUE | 14

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ends with a  
customer'...  
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Rach & Ant  
running for gold!**

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# This is Chris... He's Family.

**Chris** had his stoma 5 years ago. He is married to Rachel and has 2 children and 4 cats. He loves pickled onion Monster Munch and reviews beers from all around the world.

*"After just one phone call with Respond I was sold, as they are just so caring."*

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# A message from the Editors



Nicola Thompson

Marketing Manager



Natalie Jones

Marketing Coordinator

Hello, and a very autumnal welcome to our Autumn Issue of Connect 14. We hope you all had a wonderful Summer; we had some beautiful weather, and we hope you took advantage of it, whether at home or abroad. As we prepare for the autumn season, we bring you more 'It's A Family Thing' campaign content in this issue, where we had the opportunity to speak with our ambassadors and learn more about what they think about our award-winning prescription dispensing service. We're hard at work preparing for our Annual Stoma Care Nurse (ASCN) conference, which we're looking forward to attending in person after such a long time. Also in this issue, we share exciting news about the launch and installation of our #BeTheChange accessible signage, as well as a brand NEW feature with in-house nutritionist Sinead, which can be found on page 6.

As always, we hope you enjoy reading this issue as much as we enjoy creating it.

Thank you as always for taking the  
time to read  
Nicola & Natalie

## We'd love to hear from you...

Do you have a question? Feedback? Have a story to tell? or 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**



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**Or, write to us at:**

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Respond Healthcare Ltd,  
Greypoint Cardiff Business Park,  
Parc Ty Glas, Cardiff, CF14 5WF

# Letters to the Editors

We were thrilled to receive a handwritten letter from Edith in Perth, Scotland and couldn't wait to share it...

Dear Nicola & Natalie,

I really enjoyed reading the Connect magazine. So good to hear about other people how they manage with their stoma. I am 87 years old, I had my operation about 2 years ago. My bowel had split in two, I was told I might not come through my operation. The nursing staff told me I was lucky that the top surgeon was on duty that night at the Queens Elizabeth Hospital in Glasgow. I think he came in to see me but I was not aware of it 😊 I wish I could of thanked him also all the staff who took all the excellent care of me at my age/ He gave me a chance to go on with my life. I have a lovely stoma nurse who has been a great help to me due to me having leakages which she is helping me with as I like to get out and about. I go to a pensioners club and knitting club. I have been knitting a lot of baby hats for premature babies, I feel I want to give something back to the health service. Looking forward to the next Connect magazine.

Yours faithfully,  
Mrs Edith McComb

P.S. "Thanks to the Respond team at Perth who are wonderful. So lovely to speak to, they keep in touch with

As always, we appreciate hearing your thoughts on the magazine. It is extremely rewarding for us to create a magazine that helps others feel this way. Please keep the letters and e-mails coming.

# What's inside issue 14?

## Service

NEW to this section is Sinead McParland's Nutrition Corner. She is not only our Area Manager for Northern Ireland, but she is also a Registered Dietitian. She brings a wealth of knowledge and is ready to assist you with any nutrition or stoma-related questions you may have.

We spoke with Sam, our Care Centre Manager in Larne, Northern Ireland, and asked her a few questions about her job as well as some personal ones. And we'll tell you about an exciting new feature that DPD has introduced for you as a customer.

Pages 6-16

## Events

Events are back in full swing, and we're excited to tell you about our biggest event of the year in this issue. The annual Association Stoma Care Nurse (ASCN) event is the first face-to-face event since 2019, and we're thrilled to be there.

Next issue, we'll share our thoughts and feedback on how everything went!

Pages 18-19

## Real life

In this section, we speak with Brand Ambassador Rachel, who discusses her life with a stoma through the lens of Hirschsprung's disease. She talks openly and honestly about herself and her son, Jake.

We also spoke with Colin, who shares with us his bladder cancer experience and how he now lives with two stoma bags.

These are raw and inspiring stories, and we thank you both for sharing them with us to help support others.

Pages 20-25

## Product

In this section, we will show you a variety of products available from both Respond and Pelican Healthcare.

We also bring you news on the new eakin Cohesive seal and its benefits. We also share its brand new fresh look with you.

Pages 27-32

## Company news

This section contains exciting news about our #BeTheChange initiative. We received Welsh Parliament support, and our first installation took place in Cardiff, South Wales' capital city. We also recognise our employees' accomplishments. Rhys Matthews, our management accountant, set a goal of hiking the Welsh Three Peaks with a group of friends. And Louise Crocker, our Customer Service Advisor from Perth, Scotland, came in second place in a Race for Life, all in support of our wonderful customers. The people at Eakin are very active!

Pages 34-38

## Online

This section contains the most recent blogs and podcasts that have been performing well online. And our brand ambassadors never cease to amaze us. Not one, but two ambassadors are running marathons! Rachel is first up, with her Cardiff Half in September, followed by Ant, who is training for the London Marathon next year.

Pages 43-47

# Nutrition Corner

with Sinead McParland



Sinead McParland, our Northern Ireland Area Manager, is a registered dietitian with over 20 years of experience working with patients in the NHS and privately.

Sinead received her Nutrition and Dietetic degree from Ulster University in Northern Ireland in 2001, and she has gained Dietetic experience throughout the UK as well as in the United States.

Sinead has gained knowledge in a variety of areas, including nutritional advice for the ostomate, through her work in various acute and community settings. Sinead will be collaborating with Respond and Pelican Healthcare to help you with any nutrition or stoma-related questions you may have.

To kick off this brand-new feature, Sinead would like to share with you the importance of healthy eating and how it does not have to be expensive.

Here are her top shopping money-saving tips...

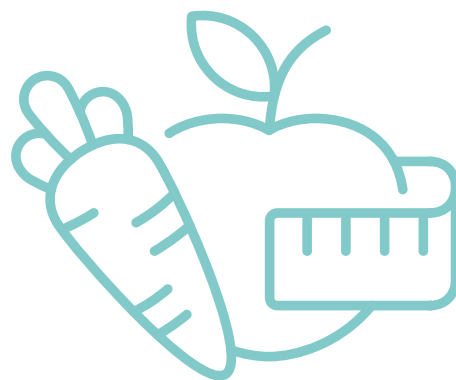
## Top tips to save money when shopping

Follow these tips when you go shopping to help you spend less:

1. Make a meal plan, particularly for your main meals.
2. Write a shopping list and check what food you already have at home to avoid buying things you don't need.
3. Select a time to shop in the week when you are not in a rush.
4. If you can, avoid shopping on an empty stomach as it may affect what and how much you buy. Consider shopping after you have eaten.
5. Be aware that special offers are not always the cheapest option.
6. Ask a member of staff at your supermarket for fresh food reduction times and try to shop then for reduced priced items. Avoid purchasing more than you need or can store. Use within the specified date or freeze for later.
7. Value brands often taste just as good for a lower price.
8. Local food markets offer locally sourced foods which are usually good value for money.
9. Cheaper products are not always at eye level or positioned obviously. Check out all the shelves (including top and bottom).
10. Larger supermarkets offer a better range of produce, often at a cheaper cost, so do your main shop there if you can.



## Cooking tips and reducing food waste



Cooking from scratch is inexpensive, enjoyable, and builds confidence! Follow the advice provided below.

1. Make your favourite takeaway food at home, for example curry and rice or stir fry with noodles
2. Make homemade soups from leftover vegetables
3. Leave fruit and vegetable skins on wherever possible and suitable. If peeling is required, some peelings can be added to recipes like soups or stews
4. Reduce your meat portions and consider having a meat free meal or day at least once per week. Replace protein sources with alternatives, for example, add chickpeas to curry or baked beans to shepherd's pie
5. Good value protein sources include: baked beans, tinned mixed beans, tinned chickpeas, lentils, some meat substitutes, milk, yoghurt, hummus, hens' eggs, frozen chicken thighs, budget cuts of meat, tinned fish (especially sardines and mackerel) or frozen fish
6. Prepare a homemade packed lunch, for example leftovers from the night before or a sandwich
7. Have a stock of herbs and spices to add flavour to meals or side dishes. Mixed herbs are good to add to most savoury dishes
8. Freeze excess food, such as bread and other perishables. Most foods can be frozen, so look at the packaging for guidance
9. Consider bulk or batch cooking meals if you can (make a large amount and split into portions). Freeze or refrigerate leftovers for convenience and to save money



Do you have a question for Sinead?  
E-mail; [marketing@respond.co.uk](mailto:marketing@respond.co.uk)  
and we will feature and answer this  
in our next issue!

# Meet the Family...

We sit down with our ambassador, Summer, who is a new ostomate, who has been using Respond for seven months...

## Tell us about yourself

I'm Summer, I'm twenty one and from Essex, England. I've had my stoma for nine months and I had my stoma because of Ulcerative Colitis.

## What do you think makes a great service?

I think what makes a great service is definitely the customer service team and how they help you. It's how easy they make the process for you to order your prescriptions.

## How long have you been using the Respond service?

I've been using the Respond service for probably about seven months now. I had issues with a previous company with them not being able to supply my bags and a lovely member of Respond came to me and said they could help. From then I just thought, well, they've managed to help me and sort the bad situation out, so I changed to Respond.

## What is it about the Respond service that you like?

I like the whole process and how easy it is. I just call up, or sometimes Respond will call me, and when I need to place my order I say "I'll have the same as last time, please". It's easy and quick. The whole process is simple. And they are also so lovely and chatty when you call!



## What three words would you use to describe the Respond service?

Efficient is one of them and the staff are so lovely...I'd go with reliable, friendly and efficient!

## What does it mean to be part of the Respond family?

It does feel like being part of a family. It's like one big community and it's so lovely to meet so many like-minded people. I feel like we're members of a team. We're together and we have each other.





## It starts and ends with the customer

Did you know... DPD is our preferred courier company to deliver your stoma and continence supplies. Why? Their values and ethos are very similar to ours in that they always put their their customers first and at the heart of what they do, which we love.



### Passion

GO THE EXTRA MILE  
TO MAKE IT RIGHT  
FOR THE CUSTOMER



### Respect

TREAT PEOPLE HOW  
YOU'D LIKE TO BE  
TREATED YOURSELF



### Honesty

LOOK AFTER OUR  
CUSTOMERS' GOODS AS IF  
THEY ARE YOUR OWN

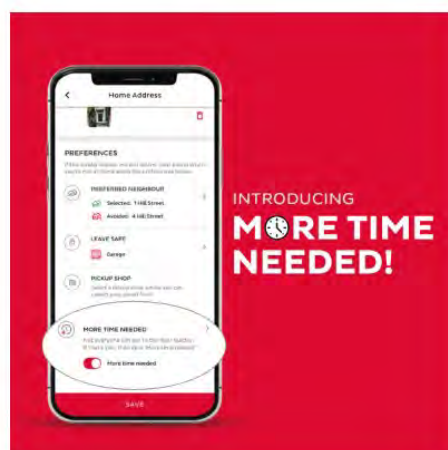
Our award-winning service is carried through from the time you place your order until it is delivered to your door, thanks to our partnership with DPD, a collaboration we are very proud of. Let us introduce you to some fantastic new features they have recently launched.

## NEW FROM DPD

## 'More time needed' option

DPD is always looking for ways to do more for their customers, and with that in mind, they have recently introduced a 'More Time Needed' option. This will allow our customers to specifically indicate to their DPD driver that they require additional time to get to the door. This is an excellent, well-thought-out addition to their service, in our opinion.

To use this service, first download the DPD App, then go to preferences within the app and select the option.



# Clean, green delivery



DPD operates over 1500 electric vehicles across England, Scotland, and Wales. They are continuing to expand and invest in these vehicles in order to put all-electric vehicles on our cities' streets.

They also promise to 'deliver green' to 30 major UK cities by 2023, and the Eco Fund will support community-based sustainable projects.

DPD has been named Sustainable Business of the Year in the UK's Business Champions Awards as a result of this, and we couldn't be happier for DPD or more proud to work with them as our delivery partners.

Respond believes in sustainability and is proud to be a part of it. DPD sends us a carbon certificate every month, and we're thrilled that over 1000 of our deliveries are made with all-electric vehicles. How wonderful is it to save 343kg of CO<sub>2</sub>, which is equivalent to planting 1 tree?

For more information, [go to green.dpd.uk](https://www.green.dpd.uk)

Respond Healthcare

## your Carbon Certificate from DPD

You're making a big difference to our environment by sending your parcels with DPD.



In July 2022 we delivered

# 1,244

parcels to Respond Healthcare customers on all-electric vehicles

Saving

# 343kg

of CO<sub>2</sub>

The equivalent to planting

# 1 tree

statement details

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 1,500 vehicles delivering 'green' throughout the UK.

Find out more at [green.dpd.co.uk](https://green.dpd.co.uk).



### A Day in the Life of Samantha McKee

Care Centre Manager,  
Larne, Norther Ireland.



#### 1. How long have you been in your role?

I have been in my current role as Care Centre Manager, Larne for 3 Years. I've been with the company for many years before becoming the Care Centre Manager, I originally joined as an apprentice through an education programme and never left!

#### 2. What does a day in the life of a Care Centre Manager look like? What are your main responsibilities?

I work closely with the customer service team in Larne, being as pro-active as possible to ensure the team are happy and confident in their roles, thus providing an excellent

service to our customers. I also work closely with my management team and various other departments of the business, attending meetings and working together to provide the highest possible standards for our customers.

#### Tell us about your team?

In Larne, we have a team of 12 made up of Customer Service Advisors, Home Delivery Service Driver & Warehousing. We have a hard-working, friendly and loyal team, always pushing themselves to ensure work is done to a high standard and the customers receive the

best possible service. I try not to be biased, but I am blessed with a great team that both work hard, but also have time for each other.

#### What's the best thing about your job?

The people – this includes the customers and working relationships. Also, I would say job satisfaction, it is very rewarding to know at the end of each day we have all tried our very best to achieve excellence and be of support to our customers and hopefully they would say we stick by our motto

*'making life better'.*



### ...And the biggest challenge?

Fine tuning the workload to ensure the inbound calls are a priority. We never want to have a customer wait on hold to get through to speaking to a member of the team. It is a constant juggle of making outbound calls, organising the workload & staffing levels to ensure there is always someone ready to take the next inbound call.

### What makes you feel proud about working for Respond?

We really do care. The customers are the sole focus of what we do in Respond, in every aspect of the jobs we do, the customer will always be the centre of our attention. I have been part of many discussions, projects, procedural changes in Respond over the years and honestly can say customer care takes priority.

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

I would say my biggest achievement in my current role would be that we thrived during a pandemic. With many huge obstacles thrown our way, we managed to ensure all of our customers still received the high standards they are used to, and most importantly, continued to receive their orders on time and in good condition. The pandemic meant a lot of big changes for us as a team, including introducing home working and very reduced staff on site, but we did it and I am very proud!

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

Experience. I have been a part of the Larne team for 15 Years. I have been

a part of a huge number of procedural changes and implementation from very early on and feel the knowledge and experience I have in Respond and it's workings help me understand my role. I have grown from a Customer Services Assistant to Office Supervisor, to Team Leader and finally to Care Centre Manager, on my first day of working for Respond Plus as it was previously known, I was age 17, so in a way I almost feel I have grown up with the company.

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

To be patient. There is a lot to learn, it is a role that cannot simply be trained out in the first weeks or months. Patience is key, it is a learn on the job type role, remain open and willing to learn and rest will all fall into place.

## How would your friends describe you?

I may have cheated on this one and asked 3 of them – their replies are: Loyal, caring & spoilt.

## What's your main hobby / interest outside of work?

I have 3 young boys to entertain, so don't get a lot of time to myself. I do love to do some shopping. I take an interest in all things make up and enjoy giving my family and friends' beauty treatments such as waxing and gel polish.

## What does your perfect weekend look like?

Quality time with my husband and 3 boys, we love to go to a park, or if rainy out do some ten-pin bowling, a family movie, and a nice meal (which may include a cocktail or two) – I am easily pleased!

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

Kim Kardashian. I would ask how she manages to balance her hugely successful and busy

life of being a mother, a businesswoman, a celebrity figure and a student lawyer – amongst other things. I know the Kardashians have a bit of a tarnished name, but I love how independent and driven Kim is in her life.

## 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

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and help us to help others.

#RespondFamily



HEALTHCARE DELIVERY REVIEWS



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### Confidence

No matter which products you use, we can dispense them.



### Discretion

Discreet and unbranded packaging and delivery



### Dispensing your prescription

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### No queuing

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### Connect

We also produce a highly commended quarterly magazine for our customers



### 1-hour delivery slot

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# Meet the Family...

Keith has been a Respond ambassador for the past two years, so we thought we would ask him a few questions about why he joined our service, and how it feels like one big family.

## Tell us about yourself

My name is Keith Thomas and I am a sixty-year-old Granddad. I have had an ileostomy for ten years now as I was diagnosed in 2008 with Ulcerative Colitis. After four years on medication, my bowel failed, and I had to have an ileostomy for life. I'm from Swansea, but I live in Llanelli and I'm a Swansea bus driver!

## What do you think makes a great service?

I would say a great service means that the products you order are delivered on time and in good condition. Customer service is also very important.

Respond call me every month. Now, I'm a busy bus driver, and I find sometimes that my phone will ring and I'm unable to answer. It's only when I stop I can call them back, but it doesn't matter who answers the phone — they are so polite, so helpful. And they don't just ask "What do you need?", they ask me "How are you doing?" and that is what's important — customer service is everything.

## How long have you been using the Respond service?

I've been using Respond service for about two or three years now. Before that, for me, it was just going back and forth to the chemist. What I found after a long time of using different chemists was that I was turning up to collect my order and they were saying "This is missing" or "That's missing". So I thought to myself, you've heard about Respond for such a long time, why not just give it a go? And I am so glad that I did it because it has made such a difference. I never run out of anything. Everything's on time. Everything's in perfect condition. I'm one happy ostomate!



## What does it mean to be part of the Respond family?

It is absolutely fantastic to be part of the Respond family. It's...how can I say...ten years ago before I had an ostomy I was very very ill. And then I had an ostomy and it gave me my life back. And now I get to sit in front of a camera, talk to people, have my photo taken, meet incredible people, and here I am having a couple of days away, enjoying my life.

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

It is absolutely fantastic to be part of the Respond family. Ten years ago, before I had an ostomy, I was very ill. And then I had an ostomy and it gave me my life back. And now I get to sit in front of a camera, talk to people, have my photo taken, meet incredible people, and here I am having a couple of days away, enjoying my life.



# Starter/Side

## Thai pumpkin soup

**Prep time 25 minutes**

**Cook time 40 minutes**

**Serves 6**

### Ingredients:

- 1.5kg pumpkin or squash, peeled and roughly chopped
- 4 tsp sunflower oil
- 1 onion, sliced
- 1 tbsp grated ginger
- 1 lemongrass, bashed a little
- 3-4 tbsp Thai red curry paste
- 400ml can of coconut milk
- 850ml vegetable stock
- lime juice and sugar, for seasoning
- 1 red chilli, sliced, to serve (optional)



Recipe card

### Method:



#### STEP 1

Heat oven to 200C/180C fan/gas 6. Toss the pumpkin or squash in a roasting tin with half the oil and seasoning, then roast for 30 mins until golden and tender.

#### STEP 2

Meanwhile, put the remaining oil in a pan with the onion, ginger and lemongrass. Gently cook for 8-10 mins until softened. Stir in the curry paste for 1 min, followed by the roasted pumpkin, all but 3 tbsp of the coconut milk and the stock. Bring to a simmer, cook for 5 mins, then fish out the lemongrass. Cool for a few mins, then whisk until smooth with a hand blender, or in a large blender in batches. Return to the pan to heat through, seasoning with salt, pepper, lime juice and sugar, if it needs it. Serve drizzled with the remaining coconut milk and scattered with chilli, optional.

James Martin via BBC Good Food:

<https://www.bbcgoodfood.com/recipes/thai-pumpkin-soup>

# ASCN 2022

Harrogate

Along with our sister company Pelican Healthcare, Respond will be exhibiting at the Association of Stoma Care Nurses UK (ASCN UK) Annual Conference in Harrogate from the 9th to 11th of October. This is the largest event of its kind in the UK where specialist stoma care nurses gather under one roof, giving us the opportunity to engage with them and to showcase our service and our products. We also look forward to networking with our industry colleagues, charities, and voluntary partners.



Association of Stoma Care Nurses UK

The theme of this year's conference will be 'Together Again – Demonstrating the Value of the Specialist Stoma Care Nurse'. The programme is filled with keynote speakers and presenters, discussing a range of topics that will enhance the practice of those involved in delivering stoma healthcare.

Alison Roberts, Respond Nurse Team Leader, has been chosen to present at the conference sharing her knowledge and experience. In addition, educational posters produced by our Respond community stoma care nurses Helen Coulter, Claire Murphy and Kim Moxham have been selected to be displayed at the conference.





**Pelican Healthcare, award-winning providers of ostomy products, and Respond, award-winning prescription dispensing service, a perfect partnership that works for you.**

We're dedicated to improving the quality of life of the ostomate and continence community throughout the UK.

Our mission is to provide service solutions and innovative products, which help create a future where people are not defined by their condition, and are empowered to make informed choices.

We are a committed partner of the NHS, supporting clinical judgment and sharing the joint vision of joined up patient care.

*there for you...*



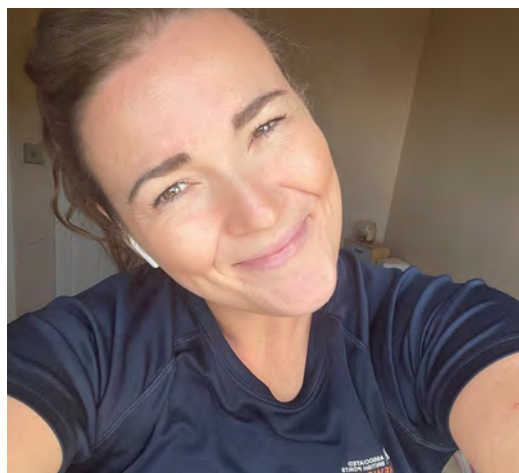
BRITISH HEALTHCARE TRADES AWARDS 2018  
NHS DAC PATIENT SERVICES

**Winner**

# Hirschsprung's and me

by Rachel Allen

I am a bit of an imposter in the ostomy community, with my reason for having an ostomy uncommon compared to most. For me it is Hirschsprung's got me a golden ticket to the club. This occurs in 1 in 10,000 births a year, and is more common in boys than girls, but more severe in girls - lucky me! Hirschsprung's Disease is caused by the genetic mutation of the RET gene during prenatal development. It causes the ganglion cells that line your intestines not to function. There is no way of fixing this, leaving the only option to remove the intestines affected. This will cause the person to require ostomy surgery. For me and my little boy (who was also born with the disease), we needed all our large intestines and 2.5cm of small intestine removed within a few weeks of birth. It is not typical that a mother and son would need the same removed, just a very unique coincidence. I believe he was always meant for me, but I guess every mother says that. Surgery is necessary for waste to leave the body, with the first signs of Hirschsprung's Disease in a newborn being distention in



the stomach, failure to pass the meconium (a baby's first poo), and little interest in feeding.

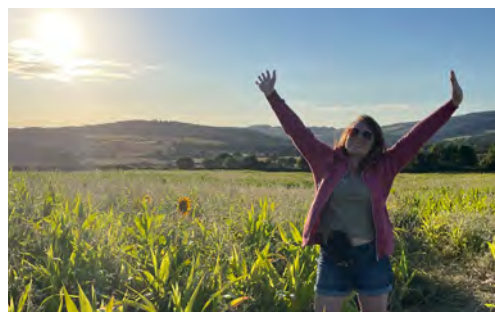
At 2½ years old my stoma was reversed. With no colon left it meant lots more trips to the toilet, a week off every 4-off school, and a lot of social anxiety just for fun! I wasn't well for most of my early childhood, and when I got pregnant with my boy in 2015 the pressure of carrying him physically caused severe pain in the rectum, to the point where it was too painful to walk. I had to quit my career as a teacher, and when my son was born with the same condition it was his health that took priority. He was so unwell, much more severe than I was. He has gone through 10 operations, an attempted reversal which went horribly wrong where we nearly lost him, and the need for a feeding tube. Despite this, he has come through it all and is living life to the full. He goes to school and is a



right old chatterbox (if you know me you might guess why that is!) and has overcome such adversity that I burst with pride every day.

As for me, in the first lockdown of Covid, I had a call to ask if in 2 weeks did I want stoma surgery, as there was nothing more they could do for me. I jumped at the chance. I knew I couldn't carry on the way I was anymore. It affected my mental health, my relationships, and I lost my career over it. It was the best thing I have ever done, and if they ask me to try a reversal again, they will have to fight me for it! I never want to go back to pre-stoma life. The thought scares me. When you have lived in chronic pain for years and then it goes, the greatest fear is waking up to that pain again.

If you are reading this it is likely you have gone through something similar, know someone with an ostomy or have one yourself. What you may see as the most common reasons online for having an ostomy is Crohn's, Colitis and IBD. What you do not see is Hirschsprung's Disease mentioned much at all. When my little boy was born, I started blogging as an outlet, to connect with other parents, and raise awareness of the condition and life with a newborn with an ostomy. I didn't anticipate that 6 years on I would still be doing it and having the honour of being a Brand Ambassador for Pelican and Respond Healthcare. It has been a whirlwind of photoshoots, blog posts, content creating, and raising money for my



son's hospital charity Noah's Ark Children's Hospital Charity in Wales, becoming a Family Ambassador for them too.

The awareness online for ostomies has become so much more than I ever thought possible, and despite not seeing much about our condition specifically, I am happy to say I have connected with some lovely ostomates who I now call friends having met offline. As I write, this, myself (@gutsy.mum) and Ru (@ru.talks.ibd) have organised an ostomate meet up in September this year, which will be our opportunity to connect with many more people. What we felt was most important was opening the invitation to all concerned with bowel disease. Not just those with IBD or even a stoma. You see a lot of support and socials inviting IBD sufferers only, which is wonderful for them, but for those of us with an ostomy for other reasons, it can feel very isolating. We look forward to welcoming everyone in whatever capacity they have their stomas, even pre-surgery people.

*Thank you, Rach x*



# Back to Better Living

**Having a stoma or internal pouch doesn't mean you have to stay indoors.**

IA is here to support those who have been through surgery to get back to a full and active life.

From dog-walking to cycling, beach days to running, your fitness can enrich your life with your stoma or internal pouch.

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E: [info@iasupport.org](mailto:info@iasupport.org)  
W: [www.iasupport.org](http://www.iasupport.org)



## My experience of bladder cancer, and helping to raise awareness

by Colin O'Sullivan

My journey with bladder problems began on the morning of Thursday 26th May 2018 when I awoke and urinated a bowl full of dark, almost black blood. This came with no previous warning and was quite frankly terrifying. An appointment with a GP was arranged by my wife for the next day and a fast track to urology was offered. This should have occurred within two weeks, however unfortunately, this failed to be sent and the GP was extremely apologetic.

On the 10th of June, I was rushed into hospital on twos and blues as my right coronary artery was 95% blocked and required the insertion of a stent and the prescription of a drug called Ticagrelor, this was to avoid the stent blocking. By the time I got a urology appointment, a tumour was identified and a TURBT (transurethral resection of bladder tumour) the operation was too big a risk of serious haemorrhage during the operation.



Following a collapse, a couple of weeks later I was rushed to hospital with retention, eventually catheterised, and spent 10 days enduring blood transfusions and constant bladder irrigation to control the bleeding. The heart medication could not be halted in the first 12 weeks following the heart attack. Eventually, the 1st TURBT operation was performed on 10th September and after a few days, home I went sporting another catheter.

After some time, I was introduced to self-catheterisation and things appeared to settle for a while, but these became more difficult to insert and a further cystectomy proved very difficult



due to the constriction of the bladder neck which resulted in another operation at the end of 2019. The operation opened the bladder neck again to allow the ongoing use of self-catheterisation.

Problems began again in the May of 2020 but by this time the lockdown was in force and attempts to get to a GP resulted in receptionists asking the UTIs (urinary tract infections) list of questions and an antibiotic prescription sent to my local chemist. These helped ease the symptoms but only for a few days and another attempt to see a GP repeated the same process until after 4 courses of antibiotics, a Dr rang me concerned about their repeated use, and that discussion, at last, resulted in a re-referral to urology.

By this time, I was passing stones, and these were confirmed by cystoscopy, and by October I was pre-op-ed for another TURBT. Unfortunately, nothing happened, and things worsened until I ended up at A & E on both Christmas eve and Christmas day in agony with blocked stones.

Following this, it appeared I had been lost on the waiting list as everyone was working from home. Within 10 days of this realisation, I was in for another operation that crushed the stones and opened the bladder neck again early in the January of 2021. Following this, I was advised that I needed further treatment and that tests were underway.

On the 4th of February, a consultant advised me that I “had a T3 muscle-invasive cancer which couldn’t be treated with chemo or Radiotherapy”. I heard this as a death sentence at the time. I was then advised that it would require a procedure known as a radical cystectomy which to you and I means the bladder needed surgical removal and I was referred to a specialist surgeon at the Royal Preston Hospital. Following further checks and scans her view was that the operation could only proceed when a second specialist team of bowel, surgeons could be available at the same time. Once all was arranged a 10-hour trip to the theatre where the bladder, prostate, and part of the bowel were removed along with lymph nodes and a few other bits in that vicinity. The outcome of all this has left me with two stomas, a colostomy, and a urostomy.

Thankfully the specialist urology nurse had, prior to the operation, informed me of the two charities “**Fight Bladder Cancer**” and “**Colostomy UK**” and the amount of useful information on their websites were immensely helpful in preparing me, to a small degree, with what lay ahead.

I was however still quite shocked by my new body image and the need to get to terms with my new routines for bodily functions. I had also become acutely aware of my incredible ignorance about bladder cancer and the impact it can have. Whilst the late Dame Deborah James raised the profile of bowel cancer, Julia Bradbury highlights breast



Cancer and Bill Turnbull brought prostate cancer into the everyday conversation I am not aware of any high-profile ambassador for Bladder cancer.

This is all despite over 21,000 in the UK being diagnosed with Bladder Cancer every year. As a result of this, I am now determined through any means possible to help raise awareness and am so grateful to Respond for allowing me to share my story with their readers.

Also, with the help of my colleagues in the Guardian Concert Band, I was able to organise a concert of popular film theme music in June of this year to raise both funds and awareness of the two charities. We had over 120 people in the audience, along with a dinosaur, and raised over £2200 to share with the charities.

I have now had a positive 6-month and annual scan and am back at work even busier than I was before. I am self-employed in property maintenance and thankful I am now able to manage virtually everything at work that I did before my diagnosis and treatment. I have certainly had to think a little more about how to approach jobs and never go to any job without my trusted back of bits that Respond supply me to cope with any occasional accidents and leaks. I now find these occur much

less often than they did initially as my competence with the pouch changes have improved.

I used to dislike painting ceilings but now must think more carefully about skirting boards as without a sensation I now have to remember to check my urostomy pouch volume before I bend down. Most of my customers have been loyal and understanding and with that and the support of my family and band colleagues, I am pretty much doing most things I did before and trying to make sure as many people as possible are aware of the signs and symptoms of bladder cancer.

If you have a urine infection that is not responding to antibiotics, experience any pain when peeing or show any sign of blood in your urine you must get checked immediately. Other possible signs can also be tiredness, weight loss, increased frequency of needing to wee, and incontinence or lower back pain. If I've learned anything from this experience, any kind of delay is only going to make things worse than they need to be. **"Don't Delay Get Checked Today!"**

Thank you,  
Colin.

## Looking for online support?

Our private facebook group is a secure and supportive community of over 9,000 people where you can find support from others with a stoma, offer advice and, if you need it, just find someone else to talk to. It's not just for those with a stoma; friends and family are welcome too. Search for 'Colostomy UK support group' on Facebook and request to join.

Our **Live Chat support** is available on our website 09:00–17:00 on weekdays. Chat with members of our team and volunteers who will be able to answer any questions you have and offer support and advice.

[www.ColostomyUK.org](http://www.ColostomyUK.org)



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seal



The most common problems facing ostomates are leakage and skin irritation.

At Pelican & Respond, part of the Eakin Healthcare Group, we believe the solution can be a simple adjustment to your stoma care routine. If you are experiencing problems due to any of the following, an eakin Cohesive® seal may be the answer you have been looking for:

- Worry about leaks affecting your confidence
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- Uneven skin due to skin folds, crevices, or scar tissue around your stoma
- Stoma changing shape and size

Using an absorbent ostomy seal as part of your regular stoma routine helps prevent leaks leading to healthy skin and a happy you, every day.

## But why eakin®?

- eakin **Cohesive**® seals are designed to prevent and protect against leaks better than any other seal by absorbing more output. In fact, they **absorb up to 4x more than competitor seals**.<sup>1</sup>
- eakin **Cohesive**® seals transform into a **protective gel**, a sign they are absorbing and this gel continues to protect your skin<sup>1</sup>
- eakin **Cohesive**® seals **easily moulds** to suit any stoma shape or size and there is a range of 4 to suit your needs.
- eakin **Cohesive**® seals are **skin friendly** even for sensitive skin

Plus, have you seen the new eakin **freeseal**®? All the same great benefits of the well-loved **eakin**® seals but only 1.8mm thin for a discreet and comfortable feel with convex pouches.

And new for 2022, eakin **Cohesive**® seals have been given a fresh new look – no change to the seals themselves, but a design upgrade that makes the cartons easier to use:

Greater discretion, with a fresh, simple and modern look

Simple, clear information on both cartons and instructions.



Internal seal gauge for small and slims variants - allows the user to know how many seals remain in the carton

Easier and quicker to identify with product variant now also printed on lid and sides.

Easy to lift peel tabs on all blisters.



So what are you waiting for? Make every day a good day and add an eakin seal to your regular stoma care routine today. Let us know how you're getting on!

To find out more or to order a sample visit [www.pelicanhealthcare.co.uk/eakin-cohesive-seals/](http://www.pelicanhealthcare.co.uk/eakin-cohesive-seals/)

<sup>1</sup> Mc Grogan G, Haughey S and McDowell K (2018) An absorbent, enzyme-inhibiting seal reduces peristomal skin complications. *Gastrointestinal Nursing* 16:1 42-4



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to stop leaks  
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<sup>1</sup>Mc Groggan G, Haughey S and McDowell K (2018) An absorbent, enzyme-inhibiting seal reduces peristomal skin complications. Gastrointestinal Nursing 16:1 42-4



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**Please note:**

If you are unsure whether a product containing a barrier film is right for you, please speak with your Stoma Care Nurse. For Scottish requests, we will need to seek Stoma Care Nurses approval first.

# Main

## Catherine wheel toad-in-the-hole with honey & mustard onions

Prep time 20 mins

Cooking time 40 mins

Serves 4



## Recipe card

### Ingredients:

- 120g plain flour
- 3 large eggs
- 275ml semi-skimmed milk
- 12 linked chipolatas or 1 large coiled Cumberland sausage
- 2 tbsp sunflower oil
- 4 rosemary or thyme sprigs, picked into smaller sprigs
- mash and veg, to serve (optional)

### For the honey & mustard onions:

- 1 tbsp sunflower oil
- 2 large red onions, halved and thinly sliced
- 2 tbsp plain flour
- 2 tsp English mustard powder
- 1 chicken stock cube
- 2 tbsp honey
- 2 tbsp wholegrain mustard

### Method:



#### STEP 1

Mix the flour, eggs and milk in a jug with 1/2 tsp salt, then set aside for at least 30 mins. Heat oven to 220C/200C fan/gas 7.

#### STEP 2

Untwist the links between each sausage, keeping them connected. Squeeze the meat to fill in the gaps, so you have one long sausage. Coil the sausage loosely and put in a large skillet or ovenproof frying pan (ours was 25cm wide.) Pour over the oil and brown in the oven for 12-15 mins.

#### STEP 3

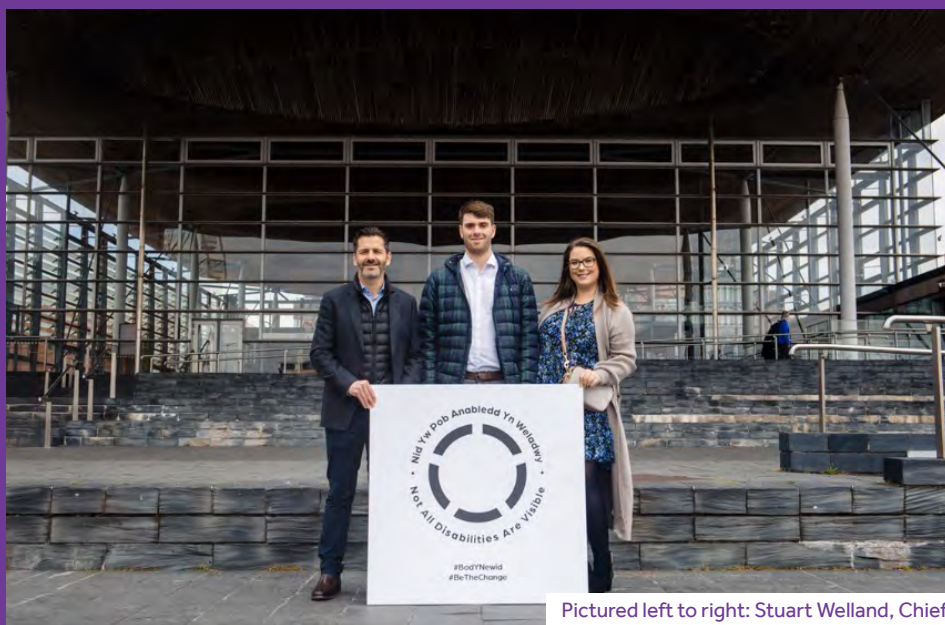
Remove the pan from the oven and carefully lift out the sausage. Pour the batter into the pan, then put the sausage back on top, scatter with the herbs and return to the oven for 25-30 mins without opening the door – the Yorkshire pudding will sink if you do.

#### STEP 4

Meanwhile, heat the oil in a frying pan and cook the onions for 10 mins or until starting to caramelise. Stir in the flour and mustard powder and crumble in the stock cube. Stir in 500ml water bit by bit until you get a smooth sauce, then add the honey and mustard and season. Bubble for 5 mins, then serve with the toad-in-the-hole and mash and veg if you like.

## #BeTheChange signage gains assembly support

Members of the Senedd Cymru / Welsh Parliament have given their approval to our new accessible toilet signage, which was created as part of our #BeTheChange campaign.



Pictured left to right: Stuart Welland, Chief Commercial Officer - Ostomy, Tristan Lee, Eakin Graduate and Natalie Jones, Marketing Coordinator.

Members of the Senedd have given their approval to our new accessible toilet signage, which was created as part of our #BeTheChange campaign.

Joyce Watson, Regional Member and Mid and West Wales Commissioner, Julie Williams, and others showed their support on the steps of the Senedd last week. Morgan, Member for Cardiff North, and Jenny Rathbone, Member for Cardiff Central.



# Senedd Cymru Welsh Parliament



The accessible toilet signage is intended to educate the public and increase awareness of the needs of people living with hidden illnesses such as a stoma. Students from Cardiff Metropolitan University designed the original sign, which was tested last year. Tristan Lee, a Swansea University graduate and mentee on the Eakin Brighter Future initiative, improved the sign design in response to feedback. The signage, a broken circle aimed at encouraging entry, is intended to be inclusive and supportive of all people living with hidden illnesses, whether it's Alzheimer's, a stoma, anxiety, or any other condition that requires people to use an accessible toilet but who don't have a visible illness.

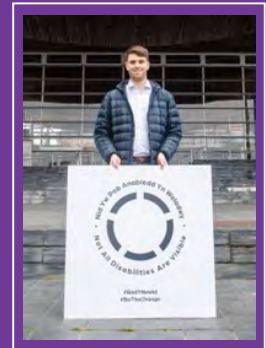
## Fresh off the press... The first set of brand new accessible toilet signs has been installed.

We are pleased to inform you that 12 of our new accessible toilet signs have been adopted and installed at St David's 2 Shopping Center in Cardiff, South Wales.

Tristan Lee, one of our graduates who helped shape the design, noticed that the shopping centre already provided free hidden disability lanyards to guests who required extra assistance during their visit.

This made him realise that our campaign would be a good fit for them and something they would be enthusiastic about and support. Tristan's proactive approach led him to contact them via their website's contact us page, where he met a lady named Eve.

They discussed the campaign initiatives and expressed an immediate desire to participate. Tristan says that the process was extremely smooth and easy. Well done Tristan!



Do you know a business who would like to adopt our accessible toilet signs?  
If so, please feel free to get in touch and email Tristan today  
[tristan.lee@eakinhealthcare.com](mailto:tristan.lee@eakinhealthcare.com)



# Spotted...

Product Manager Meg (left) and Digital Marketing Manager Nia (right) couldn't help but stop for a selfie in front of our #BeTheChange signage while out and about in Cardiff City Centre.

**Calling all South Wales ostomates: the next time you visit Cardiff, send us a selfie to [marketing@respond.co.uk](mailto:marketing@respond.co.uk).**



**To stay up to date on all things #BeTheChange, go to [bethechangeuk.com](http://bethechangeuk.com)**

## Charity in our community

# Welsh 3 Peaks Challenge

**By Rhys Matthews,**  
Management Accountant, Respond and Pelican Healthcare

On Saturday 25th June me and 14 of my friends successfully completed the 3 Peaks Challenge of climbing Snowdon, Cadair Idris and Pen-Y-Fan.

Our target was to raise £5,000 for several charities including, Alzheimer's Society, Cancer Research, MS Society, Stroke association, PSP association, Parkinson's UK, MIND and Ty Hafan. Each charity being chosen as they have impacted the groups family and friends at some stage.

I'm delighted to say that we've beaten our target, with donations as I write this currently at £5,474, so I'd like to thank everyone that has donated.

Here I am!



Across the challenge we each covered 36.5km, taking over 55,000 steps, and climbed the equivalent of 739 floors. As you can imagine there were a lot of broken bodies on the bus ride home.

Although tough (and wet) in places, it was an all-round cracking experience shared with my friends, surrounded by some of the most beautiful scenery Wales has to offer, and most importantly, for a very good cause.

Thanks again to all my colleagues who donated!

# Congratulations to our Customer Service Advisor, Louise!

Our Customer Services Advisor, Louise from our Perth office in Scotland came 2nd in the Race for Life in Kirkcaldy. She ran in memory and support for our many customers who have fought, are currently fighting, or have sadly lost their battle with cancer.

A massive congratulations to Louise, and thank you for running on behalf of our wonderful customers.





# MORE THAN A BEAR

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[www.buttonybear.org.uk](http://www.buttonybear.org.uk)



Supporting children and  
young people with a stoma

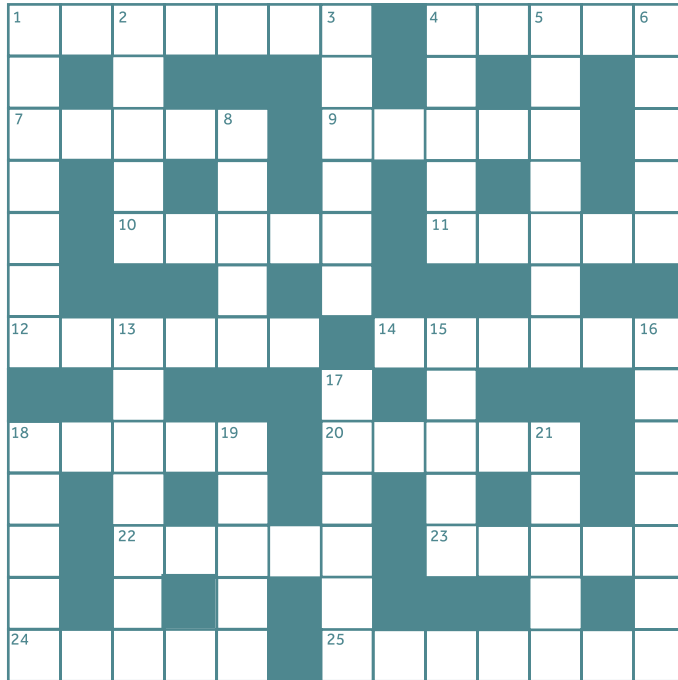
Registered Charity

A BEAR  
NAMED  
BUTTONY



# Puzzle page

## CATCH WORDS



### Across

1. Nothing succeeds like \_\_\_\_ (7)
4. First- \_\_\_\_ mail (5)
7. \_\_\_\_ and effect (5)
9. Fun and \_\_\_\_ (5)
10. Shopping \_\_\_\_ (5)
11. A drop in the \_\_\_\_ (5)
12. Fair and \_\_\_\_ (6)
14. The five \_\_\_\_ (6)
18. \_\_\_\_ and butter (5)
20. \_\_\_\_-eyed (5)
22. The \_\_\_\_ bird catches the worm (5)
23. Once bitten \_\_\_\_ shy (5)
24. A \_\_\_\_ morsel (5)
25. Snakes and \_\_\_\_ (7)

### Down

1. Trade \_\_\_\_ (7)
2. Hearts, Spades, Diamonds, \_\_\_\_ (5)
3. \_\_\_\_, sealed and delivered (6)
4. A \_\_\_\_ role (5)
5. Questions and \_\_\_\_ (7)
6. A \_\_\_\_ statement (5)
8. Trial and \_\_\_\_ (5)
13. Less than \_\_\_\_ (7)
15. Pieces of \_\_\_\_ (5)
16. Cups and \_\_\_\_ (7)
17. \_\_\_\_ and Hyde (6)
18. \_\_\_\_ of burden (5)
19. \_\_\_\_ tricks department (5)
21. Forced into \_\_\_\_ (5)

# Dessert

## Autumn crunchy crumble

Prep 20 mins

Cook 30 mins

Serves 4

### Ingredients:

- 140g plain flour
- 100g margarine
- 4 tbsp rolled oats
- 2-3 tbsp demerara sugar
- 1 tsp cinnamon
- 4 eating apples or pears or 6 plums (or a mixture)
- handful sultanas, soaked in hot water for 10 mins
- 1-2 tbsp honey
- natural yogurt, ice cream or crème fraîche, to serve



### Recipe card

### Method:



STEP 1 Heat oven to 200C/180C fan/gas 6. Sift the flour into a bowl and add the margarine.

STEP 2 Using a fork or your hands, mash together the margarine and flour until it resembles breadcrumbs and there are no remaining lumps of margarine.

STEP 3 Add the oats, sugar, and cinnamon to the flour and margarine mixture.

STEP 4 Core the apple and/or pears, and stone the plums, if using. Chop all the fruit, keeping the skin on for added flavour, vitamins, and minerals, and put in an ovenproof dish in layers.

STEP 5 Drain the sultanas and add to the fruit. Drizzle with the honey.

STEP 6 Sprinkle over the crumble mixture. Bake for 20-30 mins until the crumble topping is golden and the fruit is bubbling. Serve with a large spoonful of natural yogurt, ice cream or crème fraîche.

BBC Good Food: <https://www.bbcgoodfood.com/recipes/autumn-crunchy-crumble>

# Talk About

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# Latest blogs...

Our digital department has been collaborating with our fantastic brand ambassadors to create some really interesting blog topics. From fitness and travel to mental health and surgery, and much more. We've hand-picked a few for you to read in this issue. Take a look today...

## My Barbie Butt Surgery

@summerstoma shares her experience having recently had Barbie Butt surgery, and answers some frequently asked questions.

Scan the QR code with your smartphone or visit

<https://www.pelicanhealthcare.co.uk/summers-barbie-butt-surgery/> to read.



## Living live with two stoma bags

"Four and a half years later, I live a good life. I have adjusted well to living with two stomas. I am a passionate advocate for stomas and fellow ostomates and well as raising awareness of bladder cancer."

@2bagsforlife shares her journey with bladder cancer and living with two stomas

Scan the QR with your smartphone or visit <https://www.pelicanhealthcare.co.uk/living-with-2-stomas-lauras-stoma-story/> to read.



## Body Confidence

"Each day as I got stronger and learned my way with my stoma bag and watched as the scars healed, I began to change my way of thinking towards my body and how it looked. I learned how my scars had reminded me of wars I had won."

@big\_c\_stomaandme talks all about body confidence with a stoma and how she's learned to embrace how her body has changed.

Scan the QR with your smartphone or visit <https://www.respond.co.uk/2022/08/16/body-confidence-with-a-stoma-by-maryrose/>



We hope you've enjoyed reading our brand ambassadors' blogs. More are available to read on our websites [respond.co.uk/blog](https://www.respond.co.uk/blog) and [pelicanhealthcare.co.uk/ostomate-blog](https://www.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.o.uk**

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

# Let's Talk...

pelican  
HEALTHCARE

Let's Talk... dives into the lives of inspiring ostomates as they open up about living with a stoma. With a range of stoma-related topics, this podcast gives a platform for ostomates to share their stories with the aim of helping those who may feel isolated, alone or not understood during their stoma journey.

Listen to our latest episodes...



## Sex, Intimacy & Erectile Dysfunction

featuring Jack & Chris as they open up about how their sex lives have changed since having stoma surgery.



## Pregnancy, Fertility & Contraceptives

featuring Amy & Jennie as they talk about their journey with fertility, pregnancy and contraceptives - including complications and receiving emotional support.



## Barbie Butt surgery

featuring Ellie & Ali as they talk about living with a Barbie butt - from the highs, lows and in between.

Scan to listen!



## What's been going on online?



# Ambassador Rachel runs for Noah's Ark



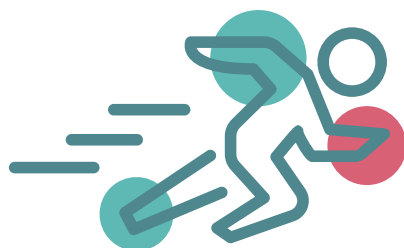
It's September, and I am pleased to say the hot weather is finally subsiding so that half marathon training is that little bit easier! It's the Cardiff Half Marathon on October 2nd and I am running for my son Jake in the name of Noah's Ark Children's Hospital in Wales. We

owe everything to the hospital, having been blue-lighted there a few hours after he was born with the same condition as myself, Hirschsprung's Disease. The condition means varying amounts of intestine non-functioning at birth, with no choice but to remove it and have a stoma.

Mother and son twinning stomas was not the dream I had in mind, but if my boy is anything to go by, anything is possible! After 10 operations at the Children's Hospital, he is smashing life and proving a stoma doesn't have to be a negative thing.

I am fundraising to give back and support the Hospital Charity in providing funding for play therapists to distract and support children during some of the worst times in their lives. Events and treats are put on to make visits more bearable. For many parents, hospital visits are not a planned event with overnight stays necessary. This is where the charity steps in and provides toiletries for parents too. Pioneering medical equipment, facilities, and family support services are all part of what has helped us navigate the last 6 years as a family. Hopefully, I can do Jake proud and complete the race knowing my little man is at the end!

Link to find out how Rachel did and to donate:



# What's been going on online?



## Our ambassador, Ant, is running the London Marathon

I'm so excited to be finally participating in the London Marathon in 2023. I've always wanted to enter it and I'm fortunate to be participating on behalf of GUTS UK charity.

Pre-surgery, one of my biggest worries was if I had to have an ileostomy, would I be able to exercise properly again?

Fortunately, the Pelican ModaVi bags help me exercise as they give me the confidence to push myself and know my bag will be coming along with me haha!

I also want to complete the marathon to help destigmatized being classed as disabled and show everyone that you can do anything, once you put your mind to it!

It's going to be a huge challenge and one of the biggest fitness and sporting achievements of my life to take part and finish the marathon. Follow along on my fitness journey and if you could make a donation that would be amazing!

See you at the finish line  
Ant

If you would like to support Ant and donate to GUTS UK please scan QR code:



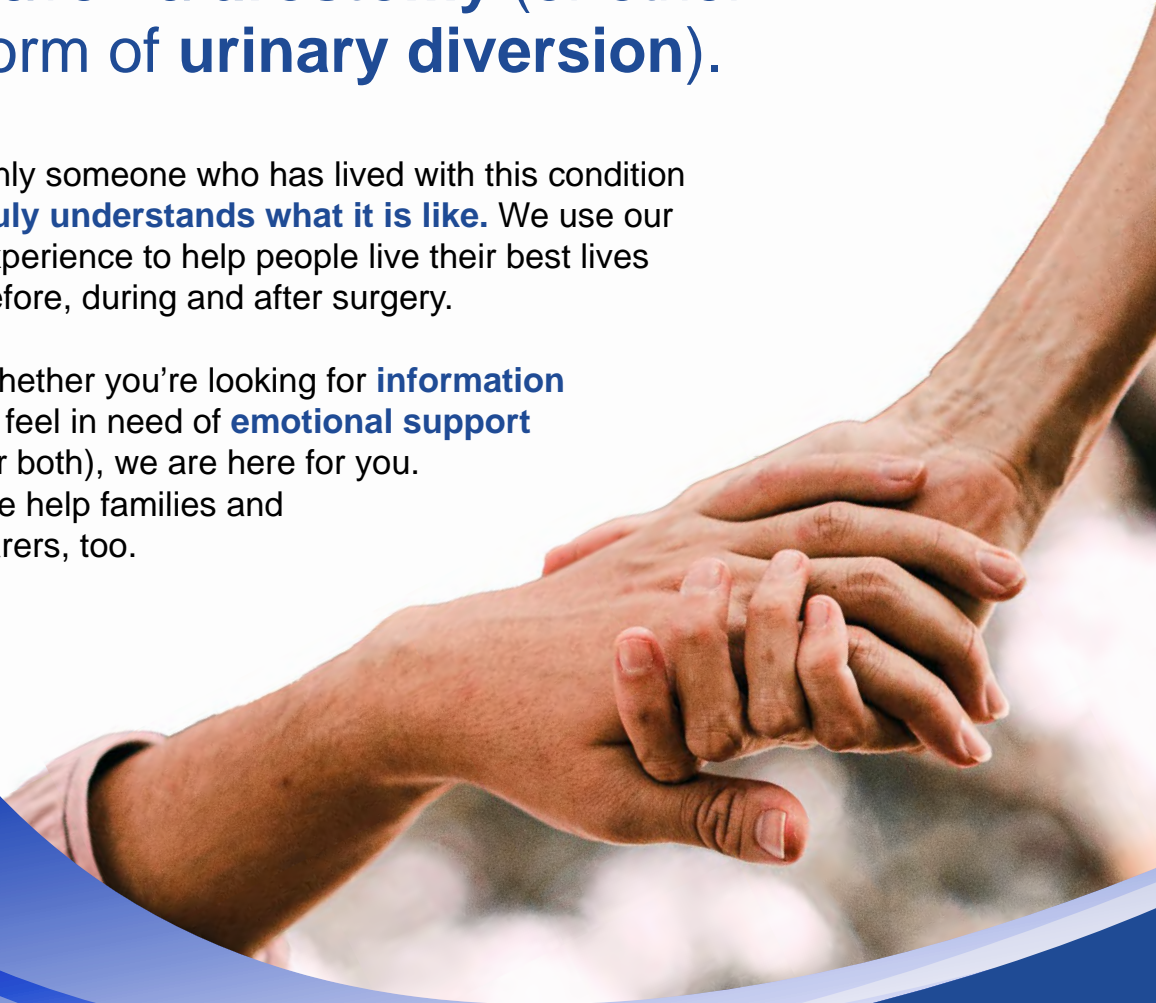




We are the **national charity** for people with - or about to have - a **urostomy** (or other form of **urinary diversion**).

Only someone who has lived with this condition **truly understands what it is like**. We use our experience to help people live their best lives before, during and after surgery.

Whether you're looking for **information** or feel in need of **emotional support** (or both), we are here for you. We help families and carers, too.



Join our friendly community today!



01386 430140



[www.urostomyassociation.org.uk](http://www.urostomyassociation.org.uk)



# Puzzle page

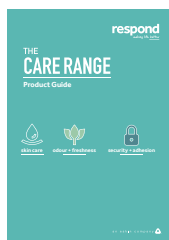
## CATCH WORDS

# Answers

<sup>1</sup> S	U	<sup>2</sup> C	C	E	S	<sup>3</sup> S		<sup>4</sup> C	L	<sup>5</sup> A	S	<sup>6</sup> S
E		L				I		G		N		W
<sup>7</sup> C	A	U	S	<sup>8</sup> E		<sup>9</sup> G	A	M	E	S		O
R		B		R		N		G		W		R
E		<sup>10</sup> S	P	R	E	E		<sup>11</sup> O	C	E	A	N
T				O		D				R		
<sup>12</sup> S	Q	<sup>13</sup> U	A	R	E		<sup>14</sup> S	<sup>15</sup> E	N	S	E	<sup>16</sup> S
		S				<sup>17</sup> J		I				A
<sup>18</sup> B	R	E	A	<sup>19</sup> D		<sup>20</sup> E	A	G	L	<sup>21</sup> E		U
E		L		I		K		H		X		C
A		<sup>22</sup> E	A	R	L	Y		<sup>23</sup> T	W	I	C	E
S		S		T		L				L		R
<sup>24</sup> T	A	S	T	Y		<sup>25</sup> L	A	D	D	E	R	S

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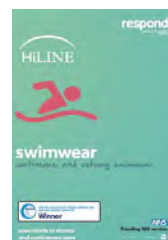
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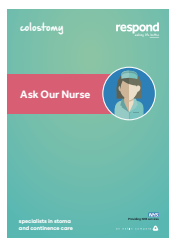
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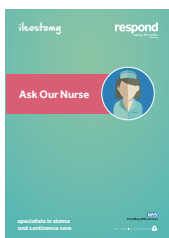


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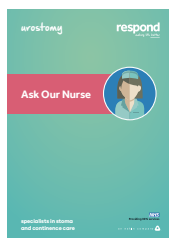
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E: [info@colostomyuk.org](mailto:info@colostomyuk.org)  
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## Ileostomy Association

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## Urostomy Association

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## Crohns and Colitis UK

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Hertfordshire  
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T: 0300 222 5700  
[www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)

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## Macmillan Cancer

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SE1 7UQ

Freephone: 0808 808 00 00  
[www.macmillan.org.uk](http://www.macmillan.org.uk)

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[community.macmillan.org.uk/cancer\\_](http://community.macmillan.org.uk/cancer_experiences/ileostomy_and_colostomy_discussions/)  
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# contact us

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# This is Laura... She's Family.

**Laura** is 45, and hails from the West Coast of Scotland. She has two stomas as a result of bladder cancer, and loves a holiday in the Caribbean.

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