

A HIGHLY COMMENDED MAGAZINE

Connect[®]

SPRING / SUMMER
ISSUE | 16

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to Pelican &
Respond's HQ**

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NEW support
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post ostomy surgery**
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respond
making life better

This is Billie... She's Family.

Billie has been a Respond customer for 3 years. She wanted to be Belle from Beauty and the Beast when she was younger, and currently dreams of being a Chef.

"Your customer service team are just fantastic, and they just make the whole thing so easy."

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



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0800 220 300

0800 028 6848 (N.Ireland)



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respond.co.uk



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with your smartphone



Providing NHS services

A message from

the Editor



Natalie Jones

Marketing Coordinator

Hello, and a very warm welcome to issue 16 of Connect. We hope you have had a lovely Winter and are enjoying the lighter evenings and warmer temperatures!

In this issue we bring you more updates of our 'It's a Family Thing' campaign with insight from our wonderful ambassadors, more real-life stories and mouth-watering recipes. We also chat to our Face of Connect, Chris, about his ostomy experience, head to page 21 to read.

We're also very excited to share with you something NEW that we have been working on with our dietitian, Sinead. Head to page 7 to find out more...

It's a privilege to share our amazing customers' stories and life events, and is definitely my highlight when creating Connect magazine. At Respond we love learning more about our customers and we also know how much our customers enjoy learning about the people they communicate with too (I know some of you reading this will know your care team by name!). So, I thought I would share some personal news with our readers, I'm excited to announce that on Christmas Day I got engaged to my partner of 9 years, and since then have been planning our wedding for May 2024! From venues, cakes and wedding dresses, it's been a busy but wonderful time!

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



Call:

0800 220 300
0800 028 6848 (N.Ireland)



Email:

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 about our Connect® magazine with fellow readers...

Dear Respond,

"You guys at Respond are absolutely amazing; I was reading the Connect magazine at the weekend. I've had Crohn's disease for 35 years and an ileostomy for 11, I think. I'd happily write something for your magazine about your fantastic service. One of the biggest concerns about having a stoma is the support you need to maintain your day-to-day independence. Everyone I've ever dealt with at Respond has always been so supportive, 100% reliable and brilliantly professional.

Thank you so much for what you do."

Paul Haines

"First, thank you for sending the Connect magazine to me. I found it very helpful, and informative. It's amazing what products there are for the ostomates. I had my stoma 67 years ago when there were very few suppliers. Look what we have today. I have also been with you for many years, it must be about 40 years at least, so thank you for your wonderful service.

Thank you,"

Barry Caplan

(Chairman of Inside Out,
St Marks, London)

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

What's inside issue 16?

Service

We are excited to announce the launch of NEW support literature, which have been created in conjunction with our dietitian and Stoma Care Nurses, head to page 7 to find out more!

We spoke with our Production Supervisor, Darren, to find out about his interests and hobbies and what makes him proud to work for Eakin Healthcare. Head to page 8 to read his Q+A.

Pages 6-12

Events

In this issue we share with you our first wellbeing event that we held in Belfast, where we were joined by our ambassador, Maryrose, and many others who provided insightful talks and demonstrations. Head to page 15 to read more.

Inside Out are hosting a Stoma Information Day in London in June, more information can be found on page 16.

Pages 15-16

Real life

We were delighted to have the pleasure of hosting little Anya and her mum and dad in our head office in Cardiff, where they enjoyed a tour of our production area and got to meet many of our colleagues in Pelican and Respond. Read mum, Amy's write up of their experience on Page 18.

We also introduce our Face of Connect, Chris, and his ostomy experience, along with inspirational stories from our customers such as Andrew, who due to a complication during surgery, had to learn to care for his stoma blind. We hope you enjoy reading their stories.

Find out more on page 18-28.

Pages 18-28

Company news

In this section we share with you how busy our social committee, Belong, has been! With food drive initiatives and litter picking, we love to serve our community far and wide. Head to page 31 to find out more.

Pages 30-32

Product

In this section we continue to bring you a variety of products available from both Respond and Pelican Healthcare, including innovative REFRESH 3in1, Pelican's urostomy pouches, and eakin freeseal benefits.

Pages 33-37

Online

Catch up with our latest blogs in this section, with topics such as self-love, managing a prolapsed stoma, and returning to work with a stoma.

We also share Amy's insightful experience and advice on addressing intimacy with a stoma. Please be mindful this blog contains sensitive topics.

Head to page 40 to read all.

Pages 40-45

We can't wait for what the future holds!

If you receive emails from us, you may have noticed a small change to our email signatures, and so we wanted to provide you with an exciting update...



Eakin
Healthcare

Working together. Improving lives.

respond

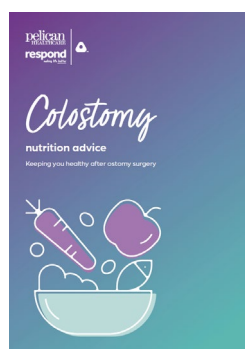
You may already be aware that Respond is part of Eakin Healthcare, and you will begin to notice the gradual introduction of our new co-branding over the coming months.

Please be assured that there won't be any change to the award-winning service we provide, just an updated look to reflect that we're proud to be part of Eakin Healthcare.

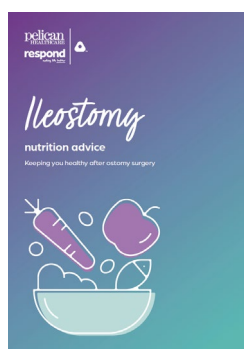
NEW support literature

In our last issue we introduced our Area Manager and Dietitian, Sinead, who is available to answer any dietary questions you may have with your stoma.

In this issue we are delighted to announce to our readers that we have created **NEW nutrition advice booklets**, which are available to request now! Covering general dietary advice and frequently asked questions, we hope you find these booklets useful.



NUTRITIONCOL



NUTRITIONILEO



NUTRITIONURO

Scan the QR code to the right or head to respond.co.uk/lifestyle/brochures/ to download your copy today!



Do you have any dietary questions for Sinead? If so please get in touch with us at marketing@respond.co.uk

A Day in the Life of Darren Owen

Production Supervisor



1. How long have you been in your role?

12 years this June.

2. What does a day in the life of a production supervisor look like?

What are your main responsibilities?

Dealing with more than 70 staff in production makes my day different every day. A typical day in my role involves organising my staff for our daily production needs, ensuring the smooth running of the department.

3. What are your favourite things about your job?

Dealing with people every day as I consider myself a great people manager.

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

I take great pride in the quality of the work we produce in the department. Showing Anya around the department & showing her the process which she found so interesting was great. Anya had a lovely day here, and it was my pleasure to play a part in that. Anya's pouch design picture is on the wall in my office.

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

We are always looking for ways to improve our production processes and seeing these come to fruition gives me great satisfaction.

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

Great communication & interpersonal skills. I take great pride in being open & honest with my staff with my open-door approach.

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

Be honest with people, treat everyone with respect & be fair with everyone.

8. How would your friends describe you?

Funny, quick witted, caring & a little bit mad.

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

Without a doubt, it's golf. I love it.

10. What does your perfect weekend look like?

Music on a Friday night with a few cold Beers. Golf. And a nice Sunday lunch with the family.

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

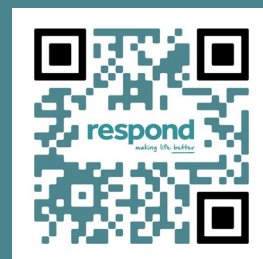
Rory McIlroy - teach me to play golf like you.

Find out more about Anya's factory visit with Darren on page 18

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

Pea, mint & spring onion soup with parmesan biscuits

Prep time: under 20 mins

Cooking time: 25 mins

Serves: 6

Ingredients:

- 1 tbsp olive oil
- knob of butter
- ½ bunch spring onion, sliced, plus a few extra to serve
- 1 potato, cut into small dice
- 1ltr hot vegetable stock
- 900g frozen petits pois
- ½ small bunch mint, leaves picked, plus a few extra to serve
- 85g parmesan (or vegetarian alternative), very finely grated



Recipe card

<https://www.bbcgoodfood.com/recipes/pea-mint-spring-onion-soup-parmesan-biscuits>

Method:



STEP 1

Heat the olive oil and butter in a heavy based pan. When foaming, add the spring onions and potato. Gently fry without colouring for about 5 mins. Stir in the stock, bring to the boil and simmer for 10 mins or until the potato is tender.

STEP 2

Stir in the peas, bring to the boil again, then cook for about 3 mins until they are just done. Remove the pan from the heat, add the mint leaves and whizz in a blender or food processor until smooth.

STEP 3

To make the parmesan biscuits, heat the grill to high. Line a baking sheet with baking parchment and divide the grated parmesan into 6 long strips. Grill for 1 min or until the cheese has melted and is lightly golden. While still warm and a bit flexible, release the biscuits from the baking parchment with a palette or cutlery knife, then cool until firm.

STEP 4

To serve, heat the soup and divide between 6 bowls. Scatter with mint and sliced spring onions, if you like, and serve with the parmesan biscuits on the side.

Meet the Family...

We sat down with our ambassador, Laura, who has been using the Respond service since her ostomy surgery and who loves to travel...

Tell us about yourself

My name is Laura Mackenzie, I'm forty-five years old and I come from the west coast of Scotland. I've had two stomas for four and a half years due to stage four bladder cancer.

What do you think makes a great service?

Something you can rely on. It's a hard journey with stomas, especially at the start, so you need someone at the other end of the phone to help you when you need it.

How long have you been using the Respond service?

Ever since I left the hospital. It's the service I was given then and it's been such a reliable service ever since. So four and a half years.

What is it about the Respond service you like?

It's the personal touch. I'm quite an organised person so I like that I can send my spreadsheet with my order or talk to someone. It's a really reliable service and I know my order will be delivered on time, which is really important to me.

What three words would you use to describe Respond?

Responsive, because they respond to my needs when I need them. Reliable, because I'm never left without my supplies. And regional – I like speaking to the team in the Perth office and hearing that friendly Scottish voice if I'm having a tough day.



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

I think you've hit the nail on the head there. I do feel part of the family. I think Respond is a company that looks out for its patients. If I can be a part of bringing that personal touch and letting new users see what's available to them then that's very important to me.

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

I would ask "What's most important to you?" I think most people would say that it's having somebody at the end of the phone and reliable service. That is something that Respond can provide.

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

I speak fluent German, and I'm a very passionate home cook so as well as my Awareness for Stomas I have a Scottish Curry Lover Instagram page. I love my holidays in the Caribbean and I'm always told that I speak too much!

Why use 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



Specialist after care education literature

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



Specialist trained staff

Our friendly staff are trained and keep in touch with you every step of the way



Multi-language support

If English isn't your first language we offer a wealth of support such as brochures and an interpretation service in over 200 languages



Connect

We also produce a highly commended quarterly magazine for our customers



1-hour delivery slot

We offer a 1-hour delivery slot

Recommend Respond today!

0800 220 300

0800 028 6848 (N.Ireland)

hello@respond.co.uk



It starts and ends with the customer

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.

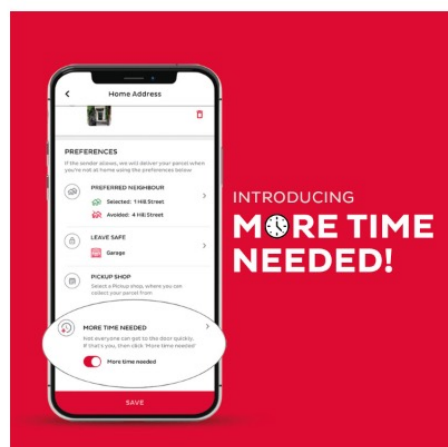
We would like to take this opportunity to remind you of the wonderful 'more time needed' feature DPD recently launched on their app, and our latest carbon certificate from DPD (on the next page), showcasing the improvements that we and DPD are making for your deliveries.




NEW FROM DPD

'More time needed' option

DPD have recently introduced a 'More Time Needed' option for your deliveries. 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, which some of our customers are already enjoying.

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





respond

making life better

your Carbon Certificate from DPD

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

So far in 2023 we delivered

3,705

parcels to Respond Healthcare customers on all-electric vehicles

Saving

1,023kg

of CO₂

The equivalent to planting

4 trees

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 3,000 vehicles delivering 'green' throughout the UK.

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

Respond & Pelican's wellbeing event in Belfast

We recently hosted our wellbeing event in Belfast at Crumlin Road Gaol, where despite the snow, we were delighted to be joined by many ostomates and our Brand Ambassador, Maryrose.

Hosted by our Dietitian and Area Manager, Sinead, we enjoyed a full day of informative talks with psychologist Dr Declan Curtis, a cookery demonstration with culinary expert, Teresa Bardon and an 'ask our panel' session with Maryrose, our stoma nurse Helen and clinical advisor Marie. Thank you to everyone who attended – we can't wait to meet more of our customers!



Inside Out Stoma Information Day, London



For all stoma patients that have a permanent or temporary stoma, irrespective of whether it is an ileostomy, colostomy or an urostomy and their families. Our aim is to provide information to one and all. Our speaker Dr Simon Gabe will be outlining IBD updates and Mr Phil Tozer will be talking about Rectal Stumps and Rectal Discharge and they will answer any of your questions afterwards.

For Further Information Tel: 07777667367



Stoma Information Day

Saturday June 3rd

**Central Middlesex Hospital
London N10 7NS**

Doors Open 10:00 am Free Entrance

**Come and meet our Company Reps
and listen to our speakers.**

All are welcome

**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**



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.

Contact IA if you'd like to speak with someone.



Ileostomy & Internal Pouch
Association
Registered Charity

T. 0800 0184 724
E: info@iasupport.org
W: www.iasupport.org



Anya's factory visit

by mum, Amy

When I first called Pelican to see if they would be interested in helping out my daughter's class for ostomy awareness day, little did we know we would meet some of the most amazing people!

At just 1-day old weighing 1lb 7oz Anya was whisked off for surgery to create her first stoma - she had this until it was reversed when she was 1yr 6 months but things did not go to plan and at age 2yr 5 months she had her stoma back and has done ever since.

Anya loves her stoma; we love her stoma but it's not something she had shared with her school friends until World Ostomy Awareness Day in October last year. Her class were all designing their own stoma bags not knowing someone in the class had one - some classmates mentioned family members, some YouTubers or people on TikTok.

On the day the winning designs were announced Anya stood up and told the whole class she has a secret superpower - a stoma! Her secret was out, and she felt great, all of her friends were so supportive!



I decided to contact Pelican because that's the make of bag Anya has always used, thinking maybe they might pick a winning design and provide a certificate, but they did so much more than that, they turned Anya into a super confident VIP!

We were invited for a tour of the factory and all her family, friends and classmates wanted to come!

As the day approached to travel to Cardiff Anya was so excited to be packing her suitcase not for another hospital stay but to travel on the train and stay in a lovely hotel for the night so that she could visit the Pelican factory! (She even told a lady on the train that was where we were heading because she had a stoma).



It was a long journey around 6 hours, but we arrived and made the most of our first night, visiting the castle and Christmas markets finishing off the evening in our pjs with a room service hot chocolate (Anya's request). It was a magical evening.

The next morning when we woke it was December 1st – Anya's cheeky elves Sparkle and Henry had come to the hotel and wanted to tour the factory too!!

We filled ourselves up with a delicious breakfast and headed for our tour – on arrival we were warmly welcomed by the staff and then Claire and Natalie – they felt like family!

Everyone we met along the way were so friendly and welcoming Anya felt like a celebrity and was thoroughly enjoying the attention from everyone.

We were kitted out in our lab coats and hair nets – Anya in her specially made lab coat and we set off with the most fantastic tour guide. Anya was so enthralled at how everything worked and making her own pouch. All the staff made a fuss of her, and she loved it.

It is a day that we will never forget, and we are eternally grateful to the staff at Pelican that supported Anya from the day I contacted them and continue to do so now.



Anya made a scrapbook of the day full of photos and facts so she could share the day with her school.

Once we were back home, we moved our medical supplier over to Respond and don't know why we hadn't done so sooner. It was all handled very quickly and smoothly; all the staff are so friendly and helpful especially Beverley, nothing is too much trouble. Anya was delighted to receive a washbag with a cuddly giraffe in it!! (The curved scissors were great too!)

We honestly cannot thank everyone at Pelican and Respond enough.

Anya is not ashamed of her stoma she is proud, it has saved her life twice, without it she would not be here.

*Thank you once again,
Amy x*



Anya with Darren during our factory tour

Would you like **more**?

More information about the latest stoma product updates.

More news from Colostomy UK direct to your inbox.

More opportunities to take part in surveys and have your say on the future of stoma care in the UK.

More access to our support literature and factsheets about all aspects of living with a stoma.

More future copies of our award winning magazine, Tidings, delivered to your door every quarter.



Get **more** from Colostomy UK by registering with us. It's free, and your friends or family are welcome to join too! Visit www.ColostomyUK.org/join-us/ or call 0118 939 1537.

Face of Connect

Chris

Hi, my name is Chris (@sydneystoma), I am 47 and I am married to an amazing woman called Rachel who has dealt with so much with my illness. I have two kids, well I say two, one is now 18 and much taller than me, so hardly a kid anymore! His name is Nathan, and I have a 12 and half year old daughter called Leah. Leah is certainly a daddy's girl and gets everything she wants! But I love it. We also have four cats and one dog. So, I live in a busy household, and I absolutely love it. I am a Sergeant in the Police, and my wife Rachel is a midwife, so we really do have very busy lives.

I have suffered with Crohn's Disease for many years, in fact I think I can date back my first symptoms to childhood, although I was only diagnosed in 2012. Getting diagnosed took a long time and many stays in hospital. I suffered horrendously with perianal fistulas and abscesses.

I suffered with these for years and eventually lost all bowel control which is just awful. I had so many surgeries to drain and cut out abscesses that it just weakened everything to the point it would not work. The pain of perianal abscesses is absolutely like no other pain, it is barbaric. So, in the end I just



had enough and told my surgeon to give me a permanent colostomy and remove my rectum, two weeks after saying this to my surgeon I was on the operating table!

My surgeon told me after surgery that it was the best decision I could have made, she said there was no way they could repair or stop the fistulas. I know it was the best decision I have ever made as I have my life back.

I look forward to sharing more of my story with you. Thank you for reading, Chris

Travelling blind:

my stoma journey and how blogging and walking helped my recovery
by Andrew & Rebecca

TW: This story contains discussions on mental health, with mentions of depression and ending life.

We recently spoke to Respond customer, Andrew, and his wife, Rebecca, from East Yorkshire about Andrew's experience with Respond, and his stoma journey.

Due to a complication during his heart operation, which resulted in him losing his colon, Andrew went into a coma and when he woke up, he'd lost his eyesight. With his supportive wife by his side, Andrew has continued to live his life to the fullest, not letting his stoma or being blind hold him back. Take a read of his inspiring story below.

I have had my ileostomy for nearly 3 years, and I have used the Respond service since my surgery, which happened during COVID. My wife, Rebecca, generally rings once a month for my supplies, or if we're in trouble we ring quicker. We sometimes get reminders to order too. We've never had any problems at all, if we need something urgently, we get it urgently. Customer service



have been very good at providing us both with advice if we've been having any problems. They always ask how everything is, which is wonderful, and if I mention anything there's always helpful suggestions. I think the service we get is great, and we're both getting the support we need. They are always very polite, efficient, friendly, and helpful, between Respond and the stoma nurse we haven't any concerns. As far as I'm concerned, I wouldn't swap from you, unless it became difficult to get my supplies from you, which has never happened and doesn't look like it ever may happen.

I like to take part at various events, and I've done a few talks on me, how important it is to stop dwelling on what you were, and work on what you are now. What you CAN be. When I do the talks, it's basically about how



I went blind and ended up with a stoma, and how I have a non-working spleen due to sepsis. It's a funny talk, I do the serious bits which takes about 5-10 minutes, the rest is about how Rebecca and I have learned to live with it. How it moved our lives forward and changed it. It's nothing like the life we used to have but its damn good one.

There's a fair bit about the fact that theatre became open to us again, which we love going to, through an audio describer. I don't know how many times we've been to the theatre this year, must be about 7 times, plus the Edinburgh Fringe where we saw 9 shows. I've walked a lot as I mention in my blog (**Travelling Blind – information at the end**), I've walked about 2,500 miles this year, and I was the first blind man to walk the Yorkshire Wolds Way. We took part in the 40th anniversary, planting trees, where I was invited to say a few words.

I'm a lucky guy, I know going in for an operation as I did and coming out of it wouldn't be seen as lucky, but if someone was having a fantastic life and broke their leg, you wouldn't say they were unlucky – you'd say, 'he's broke his leg, but he's had a great life otherwise' and I have. Except from one part of one year, which went bad, but I have a great wife who supports me fantastically. Whoever I've spoken to when I needed help, they've all been there.

When we completed Wolds Way, we made sure we knew all the points a vehicle could get to us, in case of any problems with my stoma bag, or in case of an emergency. We always take spares anyway, as leaks are reasonably common, especially if I get hot and sweaty. It's all about some extra planning to be able to cope.

Regarding my stoma surgery and how I ended up blind, I don't know exactly what happened as I was in a coma for 10 days, but I would say I went blind straight after surgery – that seemed to be when there was a lack of blood pressure which affected the optic nerve.

So, I was blind in hospital, during COVID. Whereas Rebecca was with me a few days, eventually the shutdown happened, and I also went into septic shock, which very nearly finished me off. I had moments when I was in hospital where I didn't want to carry on. I asked for a DNR when I went into septic shock. They gave me a pill, and strangely enough no one has ever discussed my depression

since then – I had no follow up. It was in COVID times, but I've had no one asking, "are you OK now?". I spoke to my own GP briefly to cut the dosage down, and eventually cut them out completely 6 months after I came out of hospital.

Rebecca and I sat down and talked about it, for me the biggest problems were having the stoma and the blindness because I can't deal with the stoma myself. I can't see it, so I can't clean it, I can't change it, so as a grown man I'm having my wife take me to the toilet. And that is a heck of a climb down from being a "grown up". Certainly, for the first 3 months coming out of hospital, I really struggled with that and cried every time. It was the most degrading thing, for me, that I have experienced. It wasn't so bad walking into doors and things – I got quite used to that! Glass doors are terrible they don't even give you a fighting chance! So that was a tough bit. For 3 months we did discuss whether I wanted to stay alive or not, because I felt I was a burden, I didn't see any future and felt I shouldn't be on earth making life difficult for Rebecca, or anyone else. We discussed it rationally and was grateful to have support from my wife, although she didn't agree with me. That gave me the opportunity to be more honest about it and express exactly how I felt at the time, which I had never done in the 60 years previously, which helped my gradual recovery.

I got off anti-depressants as soon as I could – I wanted to know exactly what I was feeling, and if I wasn't feeling great and do something proactive about it.



Once I had got a bit fitter, as after 3 months I still couldn't walk very well, it was just a few yards, and then I had a partially collapsed lung and got to the point where I couldn't walk the length of our orangery without gasping for breath at the end. But I did eventually get up on my treadmill in my garden and started to walk a bit. Once I got to the point where I could do a couple of miles, I did start to feel quite good. And it wasn't long after that that I got stupid and started walking too many miles! I must have challenges in life, and that helped. We finally got away a year after surgery for a weekend, which was terrific, there have been lots of little things that have helped make an improvement to my mental health and recovery. It's only the past few months that I've started doing the washing up again. I used to do that all the time as one of my little jobs around the house, along with the ironing (which I haven't done yet as I'm a little worried about picking the iron up the wrong way!). I've got back to doing a few basic tasks, and it's all these things that just help you move on, move



forward.

The thing that was massive for me, was the feeling that I'd lost the theatre, as both Rebecca and I love going to the theatre and watching shows. We have been looked after by a lady, who is an audio describer, who then introduced me to some of the cast of Blood Brothers, which is one of the shows we've been to see and have even become friends with some of the cast. We travelled to watch one of them in the Edinburgh Fringe!

It's all about the little bits, all the time. Doors are open, and walking!

I have plans to do a bigger walk next year with Natural England who want me to get involved with them, to promote walking for disabled people. Writing the blog has been a mammoth help, which has been very cathartic, just being able to write it all down did me the world of good, and helped me think about my situation and put it into place, into perspective. I was thinking everyday about exactly how I felt because I was trying to describe it to others, which helped me come to terms with it better. I could put the humorous aspect to it, I've always liked a bit of comedy. Most of our life is spent laughing. Building my blog from nothing to now 3000+ followers is amazing.

Something I also deal with, is Charles Bonnet syndrome, which causes visual hallucinations caused by the brain's adjustment to significant vision loss. It's not very common but happens to some people when they go blind. Now that I can no longer see, in one eye I have a very small amount of vision, which gives me some shapes at a distance. It sends mixed messages to my brain – whereas you can see something, and your brain gets a perfectly clear message of it and tells you what it is, my brain doesn't get that clear message, so it makes it up. It just gives strange images. It can sometimes last a few months or a few years. Mine is getting more severe after 3 years, so I don't think I'm going to lose it quickly.

So, what I had initially for example, was I was trying to walk from the orangery into the lounge, and there was a wardrobe in the way – when there actually wasn't. I could see this wardrobe perfectly clear, clearer than I've ever seen anything else, and I would challenge anyone to walk through it, because you just can't. I've had a sink halfway up the stairs, I constantly walk with "ghosts", which again is very rare, but if I'm out in the town with my wife for example, there's a lady who walks just in front of her, with a red coat on and dark hair, and she's been with me right from leaving hospital. If it's busier, I get more "ghosts". When I'm tired, particularly getting up in the morning, every single wall, including where the curtains are, the bed, the floor – everything, at first it used to be anaglypta wallpaper, now, it's painting by numbers, without the numbers on, so all I can see is white walls with black lines around, and that lasts 15 – 30 minutes. On an evening, I can try walking through the house, and there will be clothes hung up on doorways, when there aren't. Rebecca will see me waving my arms to push them apart, the syndrome is constantly with me. It can be very scary, I know a lady who has the syndrome scarier than I do, and when she looks into her oven a monster jumps out, scaring her. Mine isn't scary, it's just a nuisance, it can be funny on times! I just must wait to see if it goes, compared to everything else it's quite minor, for me.



My attitude to life continues to be forget what you were and look at where you are – it's my advice for everyone.

*Thank you for reading,
Andrew & Rebecca*

You can find out more and keep up to date with Andrew's journey over on his Facebook blog page. Head to:
<https://www.facebook.com/travellingblind/>
and make sure to follow!

Travelling with a stoma

By George Harper



I thought I'd like to start my story with a wee bit of a hook line:

"Stoma won't stop me now, cause I'm having a good time, having a good time, having a ball!" Thanks Brian May/Freddie!

On my many trips since having a stoma I have never found it a problem at all. I do plan ahead and ensure that I have all my supplies organised, this can involve taking 4-6 weeks supplies with me, which is superbly organised by Respond.

The very first time I travelled was to the USA (nothing in small measures, George) and I used the restroom facilities in JFK airport before catching a flight down to Miami. May as well go for gold!

Anyway, this year's travelogue started in my favourite country Portugal. I always wanted to see the west coast of the Alentejo area just north of the Algarve. This is where all the fruit and vegetables of Portugal are cultivated plus of course where the majority of their wine is produced.

I started off in Sagres and walked around the coastal paths for almost fifty miles aided by my Nordic poles. This took about a week ending up in a place called Odeceixe — in all honesty I have never seen such unspoiled beautiful beaches which as my photos will show were deserted; awesome!!

Now from a practical point most villages had bars and restaurants and it was easy to get changing facilities, however, when I was in the middle of nowhere, I just changed outside as I take the necessary supplies with me!

So that was very easy to achieve and no stoma problems whatsoever.



One of my “things I always wanted to do” was sail around the lesser known Greek islands in a yacht.

I did this in September. The boat type was called a Gulet a basic two masted schooner on which you can assist in the sailing which I did!

You have your own cabin, shower area and toilet (depending on the boat size). None of this was a problem in stoma terms, as I always had the privacy of the boats facilities (heads as they are called).

Also, we sailed, a part of the trip was on a catamaran — again no problem! On shore, on some of the islands in the Dodecanese group they only had one or two tavernas, but no issues regarding toilet facilities!

Again, my maps and pictures will show it was all worth it—only hassle is making room in your case for supplies, so I just organise my clothes accordingly.

If more shorts or T shirts required, then I buy them where I am and I logically have room available in my case on my return as my supplies of stoma equipment have been used.

I should also add that I fit in games of golf and again just in case take supplies with me in my golf bag and if needed always find a quiet secluded place to change if required.

I am currently planning my next adventure which will be a driving safari! including part of route 66 and the Californian Coast from San Francisco down to San Diego and the helicopter trip over the Grand Canyon! —All being well!

As Helen Keller said, “Through your travels keep your face to the sunshine and you will not see the shadows”.

This was a dare!



Thank you for reading, I hope this has assured you that you can absolutely travel with a stoma and live life to the full!

George

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Introducing Sam & Katy

We are pleased to introduce to our readers our newest additions to our Community Stoma Care Nurse team, Sam and Katy!

Offering appointments upon request and providing impartial advice on stoma care and products, our nurses are here to support you at home, alongside your team at the hospital.



Sam



Katy

Sam is available in the Preston area, and Katy in the Chesterfield and North Derbyshire area. For more information or to speak to Sam or Katy, please email hello@respond.co.uk



Giving back to the local community

Our social committee, Belong, have been busy since our last update!

Trussell Trust donations

Throughout February we held a group-wide donation scheme across all our sites for food, hygiene and household items, supporting the Trussell Trust's campaign to end the need for foodbanks in the UK. We were blown away with the amount of donations we received from our generous staff, and were so pleased to be able to contribute to such a worthwhile cause. See pics below!



Big spring clean

As part of Eakin Healthcare, we are committed to reducing our carbon footprint and being more environmentally friendly. In partnership with Keep Wales Tidy and Keep Northern Ireland Beautiful, our Belong team organised the first lot of litter picks at our Cardiff, Coleraine and Comber sites.



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eakin freeseal®

Managing a urostomy can be challenging, not just for your stoma care routine but the impact this has on daily activities such as sleep, comfort and exercise.



"I sometimes feel uncomfortable going out as I don't know where a toilet is, and my bag fills up quite quickly."

UROSTOMATE | 3 YEARS

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Choose your outlet

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eakin **freeseal**® is flexible and fits snugly around your urostomy – providing secure protection, even at night. At only **1.8mm thin**, eakin **freeseal**® is low profile and therefore helps with discretion and comfort. **97%** of ostomates rated eakin **freeseal**® as comfortable to wear¹.

*"As I wear a convex pouch, I am always conscious of it being more noticeable under clothes... but the flatter profile of the eakin **freeseal**® gave me more confidence as well as providing the required protection."*

Wendy, UK

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95% of urostomates found peristomal skin condition was the same or better after using eakin **freeseal**®² and **85%** of nurses considered peristomal skin had improved with use of Pelican Select urostomy bags³

Make your choice today, order samples now through Respond.

References

1. eakin freeseal® post market user evaluation report 2021. Data on file (n=56) EA-002602-RG
2. eakin freeseal® urostomates user trial 2022. Data on file (n=20)
3. eakin nurse evaluation on benefits of Urostomy Pelican (Select) Pouches - France. Data on file 2023 (n=16)

*All convex pouches should only be used after consulting your stoma care nurse

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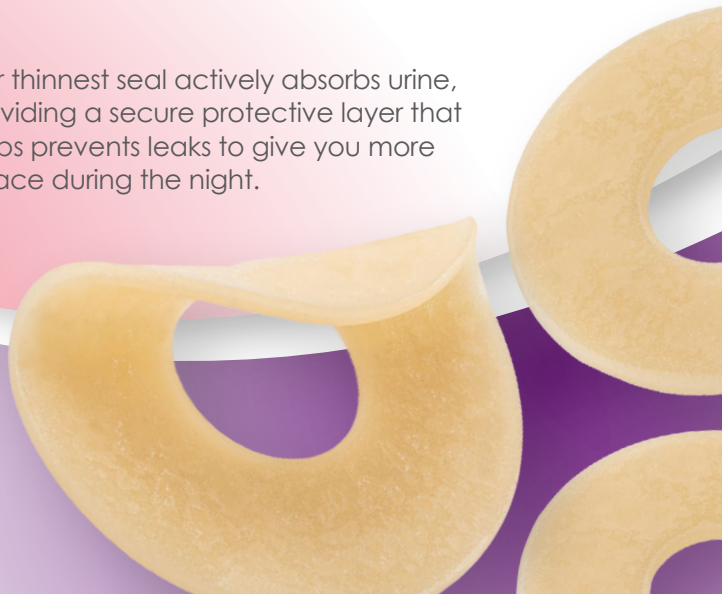
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1 Understanding Urostomies report (n=178) EA-004979-RP



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Main

Honey & mustard chicken thighs with spring veg

Prep time: under 10 mins

Cooking time: 40 mins

Serves: 2

Top Tip

This dish is rich in iron, fibre and folate. If you have an ileostomy please be mindful of your personal tolerance to spinach and frozen peas, you may wish to substitute with other vegetables if you find them hard to take.

Ingredients:

- 1 tbsp honey
- 1 tbsp wholegrain mustard
- 2 garlic cloves, crushed
- zest and juice 1 lemon
- 4 chicken thighs, skin on
- 300g new potatoes, unpeeled, smaller left whole, bigger halved
- 1 tbsp olive oil
- 100g spinach
- 100g frozen peas



Recipe card

<https://www.bbcgoodfood.com/recipes/honey-mustard-chicken-thighs-spring-veg>

Method:



STEP 1

Heat oven to 200C/180C fan/gas 6. In a small bowl, mix together the honey, mustard, garlic and the lemon zest and juice. Pour the marinade over the chicken thighs and season.

STEP 2

Put the chicken, skin-side up, on a large baking tray, then dot the new potatoes in between them. Drizzle the oil over the potatoes and sprinkle with sea salt. Roast in the oven for 35 mins until the chicken skin caramelises and is charred in places.

STEP 3

Add the spinach and peas to the roasting tray. Return to the oven for 2-3 mins until the spinach has begun to wilt and the peas are hot and covered in the mustardy sauce.

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...

Self-love & acceptance with a stoma

by Maryrose

Maryrose (@big_c_stomaandme) opens up about her journey with self-acceptance – not only to accept her stoma bag, but herself as it is: scars, stretchmarks and lumps & bumps.

Scan the QR code to the right or visit <https://www.respond.co.uk/2023/02/13/self-love-acceptance-with-a-stoma-by-maryrose/> to read.



Managing a prolapsed stoma

by Ant

What is a prolapsed stoma and how do you manage it? Ant (@ibdlife) tells the story of when he first experienced a prolapsed stoma and how he managed it.

Scan the QR code to the left or visit <https://www.pelicanhealthcare.co.uk/managing-a-prolapsed-stoma/> to read.



Latest blogs...



Working life with a stoma by Summer

Whether you're returning to work or starting a new job, it can feel daunting after stoma surgery. Summer (@summerstoma) shares her experience starting a new job after her surgery – including telling colleagues and going about day-to-day tasks.

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

<https://www.pelicanhealthcare.co.uk/working-life-with-a-stoma/> 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!

Intimacy with an Ileostomy

Amy (@ibdwarriorprincess) opens up about intimacy with a stoma – including having sex for the first time after surgery and advice when communicating with a new intimate partner.

TW: This post discusses body image, weight and sensitive topics.

Having surgery to form an ileostomy can understandably be overwhelming, especially if you'd had your ostomy formed as an emergency and it's been completely unexpected. Even for people where ostomy surgery is planned, waking up with an ostomy can feel daunting and overwhelming and it's not abnormal to feel like you're drowning, trying to get to grips with a load of information and a new plumbing system in your body.

Recovery progresses, and you start asking yourself more questions that impact your every day life as you adjust to life with an ostomy and these can be to do with so many subjects such as diet, doing sports and relationships. A topic that started to repeatedly occur in my head as I got a few months down the line in my recovery and started to feel more "human" was intimacy and how this would impact my relationship with myself and also with the man I was with at the time.



I got married in August last year to my now husband and we've been together since 2017. I had my surgery in 2011 and have had quite a bit of dating experience since between then and meeting him. I actually confined myself to just dating people who had IBD and/or an ostomy for the first few years after surgery because I was honestly so fearful of what people who had potentially never heard of an ostomy would think. However, unfortunately, I did learn by doing this that actually if somebody was going to hurt me, they would anyway,

ostomy, IBD or not and after a horrible relationship, this gave me a big wake up call to step outside away from the ostomy and IBD world.

"Am I happy with what I see in the mirror?"

Before relationships with anyone came into question, I worried about how I'd feel about my body image and whether I felt sexy or not with an ostomy bag. I had not maintained weight or even managed to put any on for pretty much the entirety of the time since my Crohn's Disease diagnosis when I was 7 years old, and I wasn't really the biggest fan of looking in the mirror or photos of myself before my surgery because I'd feel like my clothes drowned me, I looked ill and I had no shape about me, barring my swollen face ever too often from becoming dependent on steroids. Even going down a milligram on steroids would often be notorious for flinging my Crohn's Disease into a full blown flare-up.

As the months passed after surgery, I developed an appetite for food for the first time in my life that I could remember and a healthy appetite at that. Eating felt amazing and was no longer marred by the fear that came with it before surgery of being in agony, feeling sick and rushing to the toilet time after time. I started to put weight on and it was within the first few years after my surgery that I actually started

to like what I saw in the mirror and feel like a woman with shape and weight. Fast forward to 11 years post surgery and my relationship with my body is the best it has ever been. I still get my bad days, but that's human and on those days, I try to focus more on what my body and my ostomy do for me and have enabled me to do, rather than focus on my reflection.



Having sex for the first time after surgery

My partner I was with at the time, and I decided to go with the flow when it came to intimacy after surgery. It was something that, understandably, I felt anxious about and was something that I had been used to not always being straight forward or pain-free because of the relentless stomach pain I'd get with Crohn's Disease before surgery.

I can't honestly remember exactly the timeframe we waited before having sex after my surgery, but it was definitely longer than several weeks as it wasn't something I found myself thinking about in my recovery because of how close I'd been to losing my life. Getting better was higher on my priority list and I didn't really feel like I had a sex drive, again, mainly because historically I hadn't had a great sex drive from always being in pain.

When it did happen, I don't remember it being a negative experience. We took things slow, communicated and more than anything, I remember feeling a little tender but feeling a lot more at ease because I wasn't in Crohn's pain.

My stoma nurse advised that using lubricant would never be a bad idea, especially because it can be common to have vaginal dryness after ileostomy surgery. Because I also had my rectum and anus removed, she said certain positions may need adapting or require more patience and I do remember that

being more tender than anything. It felt like during sex, there was almost a limit where penetration could become sore from my barbie butt surgery and it did impact my stitches a little, because they'd done some stitches very close to my vagina, which unfortunately did become caught and sore sometimes. Thankfully, this wasn't to an extent where it became a problem or stopped them from healing and the more we became intimate, the more we learnt what positions etc were likely to aggravate this more.

Worrying about my bag getting "in the way"

Fast forward to over 11 years since my permanent ileostomy was formed and I sometimes do get irritated by my bag hanging down during intimacy, when I let it get to me anyway. There are a few things you can do to help stop this, such as using a stoma waistband to hold it up in place, using hair grips to fold the bag up in half and clip it in place once you've emptied it (if you empty it before sex) and also begin to put your bag on normally at a slight angle so that the outlet isn't hanging directly down.

My husband has also held it up for me sometimes if I've communicated it is bothering me and I have also done the same. There are also some brands that do crotchless, high waisted underwear which I haven't tried, but I imagine these are another way to keep your

bag in place and stop it irritating you or getting on your mind during sex. Pretty underwear is also a winner and can be worn and worked around intimacy. I'm happy to say that most days now, I don't really give it much mental space to allow it to irritate me during intimacy because my husband embraces me with my bag and it never stands out for him and I'm much more body confident so don't find it gets to me as much. However, there are still times where it does impact me and I communicate this and we move forward in a way that makes me comfortable together.

When to communicate to a potential intimate partner

Since having my surgery, I have always been of the opinion that the people who matter don't mind about my bag and the people who do mind don't matter. Having an ostomy bag helps you not to waste your time as it soon whittles out the shallow people who aren't meant to be with you and don't deserve to be with you whether in a plutonic, romantic and/or intimate way.

I've always been very open about my ostomy bag and have told people about it within the first few days of talking. "How?" you may ask. When I was dating, I would find a place in the conversation to mention it such as asking "tell me a random fact about yourself" and then when asked in return, tell them about my ostomy. I can honestly count on one hand the number of people who stopped talking to me and/or were bothered by it. My husband now is so supportive, embracing and loving.



Getting intimate after surgery is something that is personal to the individual and there is no set time frame or rules as to when you should feel comfortable or ready to do things, so long as you've been given the go ahead by a medical professional. The right person will happily go at a pace that is comfortable for you and reassure you, love you and appreciate you for who you are regardless of your ostomy. If you have any concerns, always speak to a medical professional such as your stoma nurse, who will be able to offer many helpful hints.

Thank you for reading,
Amy x

We understand how important sex and intimacy can be for everyone, and that this doesn't change following ostomy surgery. If you have any questions or are looking for some advice on being intimate or developing a relationship post-surgery, check out our Sex & Intimacy booklet which available online to download at: respond.co.uk/lifestyle/brochures/ or email hello@respond.co.uk to request a copy. For any further advice please consult your stoma nurse or healthcare professional.

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Dessert

Easy chocolate molten cakes

Prep time: 15 mins

Cook: 20 mins

Serves: 6

Ingredients:

- 100g butter, plus extra to grease
- 100g dark chocolate, chopped
- 150g light brown soft sugar
- 3 large eggs
- ½ tsp vanilla extract
- 50g plain flour
- single cream, to serve

Top Tip

This delicious gooey-centred dessert is vegetarian and suitable for freezing.



Recipe card

<https://www.bbcgoodfood.com/recipes/easy-chocolate-molten-cakes>

Method:



STEP 1

Heat oven to 200C/180C fan/gas 6. Butter 6 dariole moulds or basins well and place on a baking tray.

STEP 2

Put 100g butter and 100g chopped dark chocolate in a heatproof bowl and set over a pan of hot water (or alternatively put in the microwave and melt in 30 second bursts on a low setting) and stir until smooth. Set aside to cool slightly for 15 mins.

STEP 3

Using an electric hand whisk, mix in 150g light brown soft sugar, then 3 large eggs, one at a time, followed by ½ tsp vanilla extract and finally 50g plain flour. Divide the mixture among the darioles or basins.

STEP 4

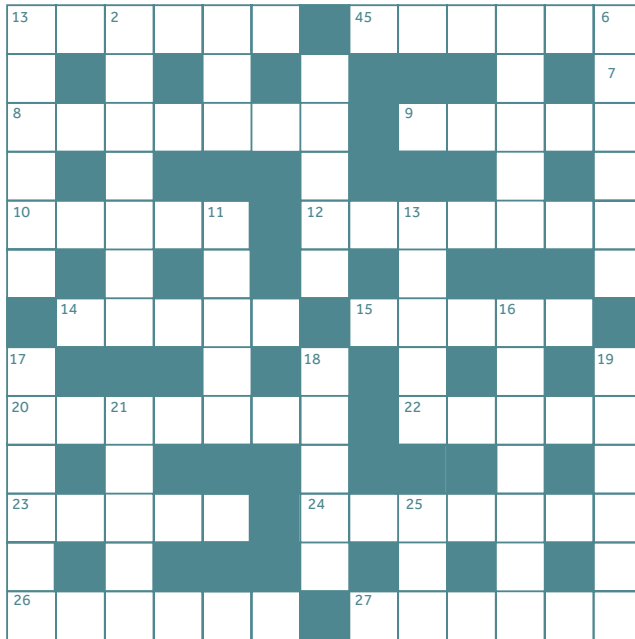
You can now either put the mixture in the fridge, or freezer until you're ready to bake them. Can be cooked straight from frozen for 16 mins, or bake now for 10-12 mins until the tops are firm to the touch but the middles still feel squidgy.

STEP 5

Carefully run a knife around the edge of each pudding, then turn out onto serving plates and serve with single cream.

Puzzle page

CATCH WORDS



Across

1. Storm in a ___ (6)
4. ___ of friends (6)
8. Boxing term, ___ out! (7)
9. Diminutive hero, Tom ___ (5)
10. Public ___ No1 (5)
12. ___ standard time (7)
14. The ___ that broke the camel's back (5)
15. The lesser of two ___ (5)
20. A snappy ___ (7)
22. ___ courage (5)
23. Business as ___ (5)
24. Rest ___ (7)
26. Walkie- ___ (6)
27. ___ fight (6)

Down

1. Tried and ___ (6)
2. The ___ Mariner (7)
3. A Grecian ___ (3)
5. ___ and effect (5)
6. ___ and flowing (6)
7. ___ faced (5)
11. Holding back the ___ (5)
13. ___ by the bell (5)
16. ___ thinking (7)
17. Do not ___ your set (6)
18. ___ and butter (5)
19. ___ boxing (6)
21. All things being ___ (5)
25. Apres ___ (3)

Talk About

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Puzzle page

CATCH WORDS

Answers

T	E	A	C	U	P		C	I	R	C	L	E
E		N		A		A				A		B
S	E	C	O	N	D	S		T	H	U	M	B
T		I				H				S		I
E	N	E	M	Y		E	A	S	T	E	R	N
D		N		E		N		A				G
	S	T	R	A	W		E	V	I	L	S	
A				R		B		E		A		S
D	R	E	S	S	E	R		D	A	T	A	H
J		Q				E				E		A
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T	A	L	K	I	E		P	I	L	L	O	W

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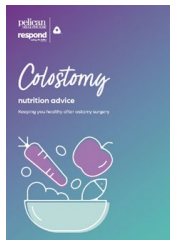

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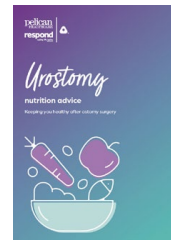

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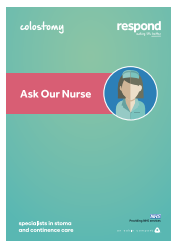
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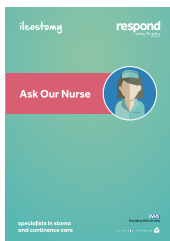
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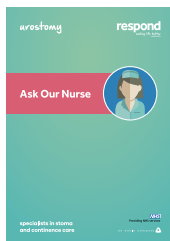

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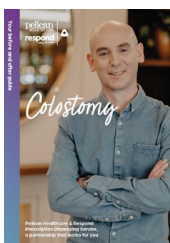

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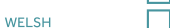

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Useful contacts

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
Gloucestershire
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_](http://community.macmillan.org.uk/cancer_experiences/ileostomy_and_colostomy_discussions/)
[experiences/ileostomy_and_colostomy_discussions/](http://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

Direct 029 2076 7880
Fax 029 2076 7881
8am to 5pm Monday to Friday
08:30am – 12:30pm Saturday

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

12 Swan Court
Forder Way
Hampton
Peterborough
PE7 8GX

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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9 York Place
Perth
Scotland
PH2 8EP

Direct 01738 629 395
Fax 01738 657 221
8:00am to 5:00pm
Monday to Friday
8:30am to 12:30pm Saturday

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36 Curran Road
Larne
BT40 1BU

Direct 028 282 60506
Fax 028 686 87999
8:00am to 5:30pm
Monday to Friday
8:30am to 12:30pm Saturday

Nottingham

97 Manvers Street
Nottingham
NG2 4NU

Direct 0115 940 3080
Fax 0115 871 8097
8:30am to 5:30pm
Monday to Friday
8:30am to 12:30pm Saturday

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