

A HIGHLY COMMENDED MAGAZINE Connect

ISSUE | 09

"All the staff are wonderful to me, I can't say enough about you!"

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Thank you to our customers


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respond
making life better

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Letter from Chris

Hello,

Welcome to the 9th issue of Connect. I sincerely hope that you and your family are keeping well in this unprecedented period of us all learning to adapt to a new 'normal' during this Covid-19 pandemic.

I'm sure you will be pleased to know that at Respond we have taken a number of steps to ensure that our teams, based in all four countries of the UK, stay safe and are able to continue working normally to ensure you receive your orders quickly. We are all getting used to a very different way of working. Some of our team are working from home, others continue to work in our offices, warehouse and pouch customisation areas, and for those who are unable to do their normal duties they are learning and doing different tasks to keep the 'Respond wheels turning'.

This issue contains all our usual features along with some very special features, including the results from our recent customer satisfaction survey. Thanks to everyone who took the time to respond to the survey. We are delighted with the wonderful comments you have written about our team, and we are pleased to share the results with you.

We are also excited to tell you about the '#BeTheChange' campaign where we are calling for changes to be made within society. Our vision is to support the need for greater understanding for people living with a stoma and more widely invisible illnesses.

In this issue we also have a feature on our business partner DPD. The timing is perfect as they are supporting us and you during Covid-19, ensuring that your orders are delivered to your door, safely and securely. Well done to all their staff and delivery drivers and we thank them for their dedication and support.

As always please feel free to contact us if there is something you would like featured in Connect.

Please stay safe and keep well.

Regards

Chris Cochlin,

Director of DAC Services



BRITISH HEALTHCARE TRADES AWARDS 2018
NHS DAC PATIENT SERVICES

Winner

Connect

What's inside

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"All the staff are wonderful to me, I can't say enough about you!"

We recently had a wonderful conversation with one of our lovely customers Eiry Halpin from Llanelli, and had an opportunity to ask her openly and honestly a few questions about our award-winning service. This is what she had to say;



1. **How long have you had your stoma?** 7 years this xmas. It was Christmas day 2012, I had cervical cancer and had septicaemia, which lead to me having my Colostomy (spread into bowels). I had had a hip replacement and had recently cracked my shoulder also. I was in hospital for 4 months.
2. **What type of stoma do you have?** Colostomy – I call him Charlie!
3. **How long have you been on the Respond service?** About 4-5years, I can't remember who I had before you, but it wasn't as easy.
4. **How did you hear about our service?** My friend recommended.
5. **Have you ever had any issues with the service?** Nothing at all. I think when I came out of hospital the SCN recommended something else, but just to have the supplies delivered to the house is amazing. I have recommended my friend to use your company, you gave him a call and he is pleased with the delivery as well.
6. **Do you ever have any problems getting through on the phone?** Not at all. Nothing at all to complain about. Normally I speak to Ceri or James in Welsh.
7. **How do you receive your goods?** I get the Welshcakes ready for when they come! I'm just so grateful since I had my hip replacement I have to use a stick, so to have them deliver is amazing. They know to leave it in a safe space for me as well.

8. What sort of support do you get from the service? Wonderful. When I can't get the support from elsewhere, I can always rely on Respond. They cut my bags for me as well, marvellous. It's just having the reassurance that they are going to be delivered, you never know when you will have any issues, my order varies, and Ceri and the team have been very understanding about that.

9. What do you think of your Respond team? If you could sum them up in 3 words what would it be? Reassuring and wonderful because of your effectiveness and how you are to me. I am never out of pouches, I wouldn't know where else to go! I'm lucky I've got you.

10. What worried you about changing? Nothing, I hope it doesn't stop that's all.

11. Why did you decide to change? A friend's recommendation, just having my items delivered to suit me. Having my items come from Cardiff as well is great. I've had no trouble at all. It's a big thing to live with, I can't understand my friend who has to fill in her prescription and collect from the chemist – I have told her to give you a call!

12. How easy did Respond make it for you to change? Yes. Everything was taken care of for me, and then it was just delivered.

13. What is it you particularly like? Can you name 5 things? I go to a lot of concerts, and I like the packs of comp items you provide, that I can take on the go in my bag. I like everything about the service! I also like your sprays.

14. What advice would you give to somebody reading this about changing where you get your supplies from? Go for it, but as we're getting older, we don't like to change, but I would still advise to try your service.

15. How likely would you be to recommend Respond? I would recommend anyone, anytime to use your service.

16. What would you say to someone thinking about changing who were worried that it was going to be difficult? I just tell them to ring you up!

17. If somebody was worried about getting their supplies from somewhere else, would you suggest that they try Respond for just one order and gave the service a go? Yes, I have told people and said to use you.

18. Where would you say we could improve? Nothing at all. I went to Tenby and ran out of supplies in Tenby and within a day I had my supplies delivery! I couldn't get over the quick delivery. I can highly recommend you.

"Without Respond I wouldn't have coped with my Colostomy so well. I can't praise you enough."



"Thank you so much
for an excellent
service, I would
recommend it to
anyone"
Keith, Llanelli

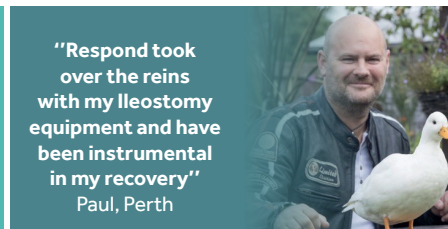


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making life better

AWARD-WINNING PRESCRIPTION DISPENSING SERVICE



"Respond took
over the reins
with my ileostomy
equipment and have
been instrumental
in my recovery"
Paul, Perth



"Very helpful,
and very
understanding"
Lauraine, Kidwelly



Professional, friendly
and reliable.
Everyday, we make
life better.

A service to smile about

99.5%

of our customers say
we are **very good** for
holding stock of all
products

99.7%

of our customers
say the quality of our
service is **excellent**
or **very good**

99.7%

of our customers
would recommend
us

Get in touch to find out more about our service



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0800 028 6848 (N.Ireland)



respond.co.uk

**specialists in stoma
& continence care**

Data on file

NHS
Providing NHS services

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Service word search

Can you find all the words related to our award-winning service?

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

STOMA - EFFECTIVE - FRIENDLY - DILIGENT - DEPENDABLE -
CONVENIENT - QUICK - ILEOSTOMY - HELPFUL - POLITE - SERVICE
- COLOSTOMY - EXCELLENT - AWARDWINNING - FRIENDS - DPD -
PRODUCTS - UROSTOMY



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Is your support garment still effective?

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Order online or call us now
respond.co.uk

0800 220 300

0800 028 6848 N.Ireland

Light Support Level 1



CCWBN15 – Support belt

Medium Support Level 2



Res 9 - Activ belt

Firm Support Level 3



Res 6 - Breathable Stretch belt



**specialists in stoma
& continence care**



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Starter

Asparagus Tart - quick and easy!

**Cook time 15 minutes,
Serves 2**

Who doesn't enjoy a tart of some description, but sometimes you just don't have the energy or time to put into making one from scratch? I buy puff pastry, chuck some toppings on and stick it in the oven for 15 minutes or so and voila! Quick and easy tea with minimal effort but plenty of taste. Stephie aka (Colitis to Ostomy) has shared with us her delicious asparagus tart recipe...

Ingredients:

- Puff pastry – ready rolled
- Fine asparagus tips
- Ball fresh mozzarella
- 1 egg



Recipe card

Method:



1. Preheat your oven to 180c
2. On a baking tray lined with baking paper, spray with oil and place the pastry onto the paper.
3. Crack your egg into a glass and mix (add milk if you wish) then brush on the pastry to form a glaze. With a sharp knife gently score a border on the pastry.
4. Break off the ends of the asparagus or trim to fit the pastry. Place your asparagus onto the pastry - it is up to you how you do this, but I found that vertical works best and is more evenly spread than horizontal.
5. Place into the centre of the oven for 12 minutes.
6. After the timer has finished remove from the oven and start tearing pieces of mozzarella off and just drop onto the tart in any way you fancy. I have found that if you do it this way round rather than the cheese first you aren't left with soggy pastry! Which if you have ever had soggy puff pastry before you will know isn't pleasant.
7. At this point you can add any herbs you fancy I of course added chilli flakes! Put the tart back into the oven until the cheese has melted and then enjoy!

£213 A DAY MEANS NURSES LIKE SHARON CAN BE RIGHT THERE WITH YOU

Macmillan Clinical Nurse Specialists (CNSs) treat and manage patient's health concerns and work to promote health and wellbeing. They use their expertise in cancer care to provide physical and emotional support for as long as its needed.

It costs £213* per day to keep this support going.

Sharon, Macmillan gynaecology clinical nurse specialist

0300 1000 200
macmillan.org.uk/donate

*Costs shown are the full cost of employing a Macmillan nurse (including oncosts such as national insurance and travel costs) in 2018.

MACMILLAN
CANCER SUPPORT
RIGHT THERE WITH YOU

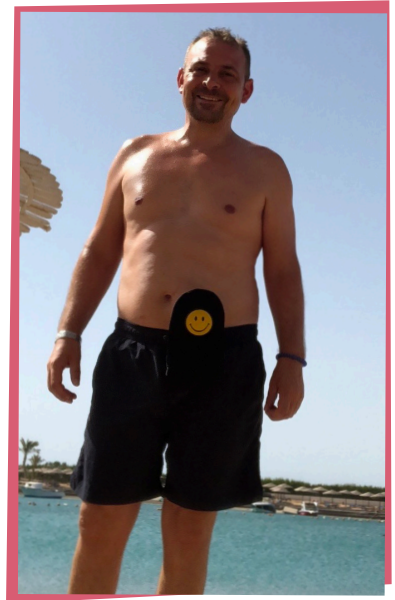


Face of Connect

Mike Blake

📍 smiley_stoma_17 🐦 Smiley_Stoma_17 @SmileyStoma

I'm Mike Blake 43 from Northampton. I was diagnosed with Crohn's disease in 2013 and I had my first colostomy in January 2017 due to my sigmoid colon being diseased and part of it removed. I ended up with a hernia 6 months later. My surgeon agreed to me having a reversal in August 2018. The reversal failed, the part of bowel they tried to reattach flaked away and I ended up with sepsis and pneumonia. I was on intensive care for 2 weeks. My hospital have been brilliant with support ever since and my stoma nurses are always at the end of the phone if I needed a chat. Intensive care also offered sepsis support a few months after leaving hospital. I have two African grey parrots called Alf and (Mad)Monty. I DJ and exercise in my spare time. I wanted to thank Respond for an excellent and super quick delivery! Just wanted to shout out to the doctors, nurses and everyone involved with the NHS dealing with the coronavirus doing such a brave job helping others.



Every year we
annual satisfaction
our customers,
we

98%

Of our customers are
very satisfied with our
pouch customisation
service

99%

Of our customers are
very satisfied with the
time it took from
order to delivery

99.7%

Of our customers say
we are **very good** at
providing an
efficient service

99.5%

Of our customers say we are
very good for holding
stock of all
products

99.3%

Of our customers say we
are **very good** at the
service we
provide

99.5%

Of our customers say we
are **polite** and take the
time to **listen**

A E
Thank
from
YO

Thanks to
taking the
answer, we
away with
kind words
award-
service, a
so pe

specialists in stoma
& continence care

we send out an
action survey to
and the results
are

BIG
Thank you
us to
YOU!

you all for
e time to
are blown
h all your
about our
winning
nd we are
roud!

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NHS

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Celebrating International Nurses Day

Present at some of life's most precious moments, and there to hold our hands through the most devastating. Now more than ever it's important to acknowledge the contributions made by all the amazing nurses throughout the world.

Nurses day this year also marked the 200th anniversary of the birth of Florence Nightingale, and the first ever World Health Organisation designated year of the Nurse and the Midwife. A special day to help acknowledge and say "Thank You" to all the nurses and midwives for all that they do, especially during these times.

Our own team of wonderful Community Specialist Stoma Nurses (or SCNs) have shared their tips and how they are finding working during these times.

Firstly, some words from our Lead Stoma Nurse, Alison, on how this situation has changed how many nurses are working and how they are meeting their patient's needs:

My role most days usually involves helping at two acute hospitals, this I do in the mornings working with the Colorectal Nurses, and in the afternoons I provide community visits to the patients that are discharged from Hospital. Initially when COVID-19 started we were screening all patients by telephone before a home visit was carried out to ensure they weren't displaying any symptoms.

At the beginning of March hospitals were preparing for the virus, all visitors were stopped and clinics were all held over the

telephone. Walking in the hospital was slightly eerie as there was no one other than staff in the corridors and on the wards. In some of the hospitals general wards were closed to patients and transformed into Intensive care units making more ITU beds available with ventilators.

In the UK, we have a group of stoma nurses that evolved from World Council of Enterostomal Therapists (WCET) some years ago and we work very much with WCET still. We are the Association of Stoma Care Nurses UK (ASCN). Due to patients no longer being able to receive home visits the ASCN quickly produced a self-help guide for patients. Our practice now is that we phone patients at home the day after they have been discharged from hospital and ask all the usual questions about diet, sleep, stoma management and general well being. Patients are invited to email/text/WhatsApp pictures of their stoma/skin if they are concerned. Depending on the outcome of the call they are sent skin protection treatments or new pouches to try if necessary and advice on high output etc is given if required. Phone calls are repeated as often as it is necessary maybe two or three times per week. All patients are required to be self-caring or live with some one that can care for their stoma 24 hours per day usually but it is even more important at this time. Once we have made the initial phone call we also send the ASCN self help guidelines out to patients and ensure they are registered with Respond for their supplies.

If you need support or have any questions about your stoma, please get in touch with your Stoma Nurse, or respond.co.uk/our-nurses/

Turnover to see how our nurses Ruth, Pauline and Christine have been working during lockdown.

NURSES

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NURSING THE WORLD
TO HEALTH




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Christine's tips for dealing with lockdown or isolation

There have been lots of thoughts and feelings during the COVID-19 situation, initially trying to understand what was happening, trying to comprehend the crisis unfolding all over the world, and adapting to a new way of living with massive restrictions to daily activities taken for granted.

My tips for anyone dealing with lockdown or isolation are:

1. Keeping connected with family and friends
2. Take up hobbies you enjoy
3. Most of all, try to have a little bit of fun - keep smiling and laughing.



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Pauline's new way of working during lockdown...

Lockdown has opened up a new way of working.

As a community nurse I visit patients at home to support them with their new way of life with a stoma. My job is very hands on but the pandemic has changed all that. I am now using WhatsApp video calls to my patients. Luckily the new patients who need the most contact are all familiar with WhatsApp and are happy to use it with me.

The video calls are allowing face to face contact and an opportunity to view their stomas and their routine and offer advice and support.



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Ruth's advice on dealing with stoma issues during lockdown

In line with government guidelines, although home visits are not available at the moment, if you have any concerns regarding your stoma please contact your nurse as they will probably be able help solve the problem over the phone. Don't leave it, especially if you are having pouch leakages or sore skin.

Your nurse is still there for you.



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BRITISH HEALTHCARE TRADES AWARDS 2018
NHS DAC PATIENT SERVICES

Winner

#InternationalNursesDay

Main

Spaghetti Bolognese – simple and yummy!

**Cook time 20 minutes,
Serves 4**

Ingredients:

- 1 x Red pepper
- 90g mushrooms, sliced (optional)
- 1 x Onion
- 400g can tomatoes or chopped tomatoes
- 500g lean minced beef
- Cheese to serve
- 350g spaghetti
- 2 tbs Tomato puree
- 1 tbs Worcestershire sauce
- 1 x beef oxo cube with 300ml water
- 1 tsb Oregano



Recipe card

Method:



1. Chop up your veg.
2. Fry them in some oil.
3. Once soft add in the mince.
4. Let the mince brown.
5. Add the oxo cube, Worcestershire sauce, tomato puree and mix well.
6. Stir in the chopped tomato, oregano, and add gravy granules.
7. Now let it simmer for 15 minutes then boil the kettle add boiling water in another pan.
8. Add a good pinch of salt and your spaghetti to the boiled water cook for 10 minutes.
9. Strain your pasta under cold water.
10. Put the spaghetti on a plate and top with Bolognese and cheese.



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Working in partnership with DPD

As most of you are aware, DPD are our chosen courier company to deliver your stoma and continence supplies. We see their values, and ethos being very similar to ours. They put their customers first, at the heart of what they do, and we love that. Caring about what is important to them – you, our customers.

It
starts
AND ENDS
with THE
CUSTOMER



Honesty

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



Passion

GO THE EXTRA MILE
TO MAKE IT RIGHT
FOR THE CUSTOMER



Respect

TREAT PEOPLE HOW
YOU'D LIKE TO BE
TREATED YOURSELF

We recently sent out a customer questionnaire, and the feedback we received around DPD deliveries was just fantastic. It was wonderful to read and knowing our customers are extremely pleased with this service really makes us happy. We know how important the delivery of your medical supplies is to you. Here are some of the testimonials we received.

"The thing I most like when I ring to place my order the phone is answered very quick and the fact I am told when and time slot it will be delivered by DPD on time as well. Knowing I can ring Respond if a problem happens and the call is free – wonderful"

"DPD are excellent and give you a delivery time slot! The service and the very helpful team on the phone"

"You always text to let us know that the script is on the way - DPD always text with a time slot! Speed and professionalism - staff always polite - nothing too much trouble! "

A day in the life of a DPD driver

Nigel Woodward



Local DPD driver - Dudley depot | Route: Stourbridge (DY8)
Length of service: 26 years

1. What's your record number of stops in one day?

122

2. How many miles do you drive per day?

65 miles

3. Who's your favourite customer and why?

Can't single one out as I have a great relationship with all of them.

4. What's your main hobby / interest outside work?

Football mainly and sport in general, also gardening and socialising.

5. In your opinion, what qualities do you need to be a great driver?

Patience, good manners, common sense, good organisational skills and good face-to-face customer service.

6. Who makes your lunch and what do you have?

I love a ham salad sandwich which either my wife or I make.

7. In what ways do you think DPD Local is better than our competitors?

How good as a business we are at delivering in the 1-hour window, also the inflight messages sent to customers and the way they can track their parcel.

8. What's the best thing about your job?

My boss Duncan (Haha)... Oh and meeting people and going out of my way to do my job the best I can.

9. If you could take one famous person out on the road with you for a day, who would it be and why? And what would you talk about?

David Attenborough, I would love to hear his stories in that soothing voice, although I would not have time to talk much as I'm far too busy.

Working in partnership with DPD we really find it insightful hearing a day in the life of their drivers.



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www.urostomyassociation.org.uk

Nutrition & Hydration week

We always support Nutrition and Hydration week which was back in March – it's aim is to highlight and promote nutrition and hydration locally, nationally and globally. We feel these are important topics for everyone with a stoma or continence issues so we reached out to our team of Community Nurse Specialists for their top tips.

We hope you will find these useful, and should you have any recommendations of your own, we would love to hear from you.



Christine's top tips for Nutrition & Hydration Week - post ostomy surgery:

Substitute fresh fruit and vegetables with frozen and tinned
Make sure you keep up your water intake - try flavoured still water

Try drinking crushed pineapple juice to excite tastebuds

Try eating 6 small meals throughout the day, eat them from a side plate to help with portion control

Try to avoid long periods without eating, as this may cause some issues with flatus

If you live alone try batch cooking meals - this will help keep you rested whilst recovering from surgery

If you have a newly formed Ileostomy and are craving nuts, try smooth peanut butter as an alternative



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Lynette's tips for Nutrition & Hydration Week:

As long as you're not diabetic, eating foods with gelatin in will help to thicken output, for example: marshmallows, jelly babies, gravy.



If you have a high output stoma try to eat bananas to replace potassium, salted crisps to replace salt and drink either St Marks Solution or Dioralyte sachets (depending on severity) if you are dehydrated.



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Ruth's tips for Nutrition & Hydration Week - Colostomy:

To reduce flatus:

1. Drink probiotic drinks daily at breakfast
2. Eat crystallised ginger
3. Drink Schweppes Peppermint cordial in hot water

To prevent constipation:

1. Drink 6-8 cups of fluid a day
2. Have Weetabix/ bran cereal for breakfast
3. Include a selection of fruit and vegetables a day



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Ruth's top tips for Nutrition & Hydration Week - Urostomy:

Drink a minimum of 6-8 mugs of fluid daily

Include cranberry, if allowed with medication taken, or lemon or blackcurrant cordial daily to help reduce mucus production and urine infections

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Ruth's top tips for Nutrition & Hydration Week - Ileostomy:

- 1 Chew all foods well and always drink fluids when eating
- 2 Avoid skins i.e. grapes, tomato skins, nuts, popcorn
- 3 Eat little and often to thicken up output
- 4 Include probiotic drinks or yogurts as part of a daily diet
- 5 If taking Loperamide medication always take it 30mins before food

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We understand

We've been there too



Ileostomy & Internal Pouch
Association

Listen • Inform • Support

**The physical and psychological impact following
stoma formation is life changing.**

The impact is not something that can be dealt with in days or even weeks. How do we know... because we've been there.

IA has an extensive network of qualified visitors who have a wealth of personal experience ready to offer support.

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E: info@iasupport.org

W: www.iasupport.org



Small changes, big impact

Pelican & Respond Healthcare are behind a movement to improve the lives of people living with stomas. Campaigner Amber Davies explains why.

Those who live with a chronic illness know all too well that it isn't just the physical symptoms that can present challenges. Very often, a lack of public understanding can mean that everyday life suddenly becomes laden with unnecessary obstacles. Even changes as seemingly minor as altering toilet signage could bring untold benefits, explains group member Amber Davies (right). "I've experienced negativity because of my condition. When using accessible toilets, people have been verbally abusive because they think they aren't for me, and I've even been questioned by security guards." The group is currently working with the Welsh Government to replace the current wheelchair symbol to reflect the fact that not all health issues are immediately visible.



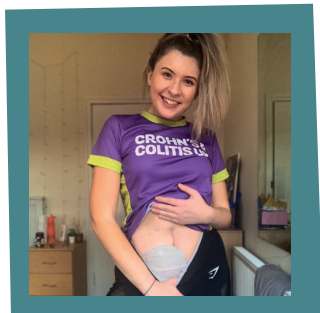
Waste collection is another issue. "Because of my stoma, I use up the space in my bin very quickly, which can often leave me facing a fine from the council," Davies explains. The group is calling for the widespread adoption of specialist collections that only a handful of areas already offer. "There has to be a greater recognition of the needs of people living with a stoma." Mat Stratton, MD of Pelican and Respond agrees: "We need more education and a higher level of awareness. People are experiencing issues every day that can be tackled positively, so we'll be working with charities and associates to form one unified voice in calling for change."

#BeTheChange

pelicanhealthcare.co.uk
respond.co.uk



Meet the #BeTheChange Panel...



Amber Davies

Stoma since 2015 due to Ulcerative Colitis

"Recently, I encountered a particularly bad experience at a pub chain and was wrongly confronted and accused by door staff of using the accessible toilet for inappropriate reasons."

"It's great to be involved in tackling the stigma and difficulty of having a stoma and/or hidden disability by taking on key issues such as changing toilet signage and developing specific waste collection services in order to better the lives of people living with a stoma."



Angelina Truman

Stoma since 2010 due to Crohn's Disease

"I've heard so many horror stories of ostomates being confronted when using a accessible toilet. As an ostomate this saddens me to think that the general public can be so cruel. These stories have terrified me and caused me to never use a accessible toilet again."

"Let's be the change that this world needs."



Allan Jeffries

Stoma since 2010 due to Cancer

"Whilst having a stoma can be classed as a disability under the Equalities Act, I have never considered myself as having a disability, just having a different way of going to the toilet. It soon became apparent that suitable toilets for the disabled are not provided as the norm for instance in pubs and restaurants. As a result, I began to choose where I had an outing to ensure that I could access suitable disabled facilities."



David Bevan

Stoma since 2000 due to Cancer

"I have to empty the bag fairly frequently; and will change the bag every 48 hours. Bag changing takes about 15 to 30 minutes and, if there has been a leak, requires me to undress to remove wet clothing, as well as to fit the new bag. The larger area inside accessible toilets is therefore very necessary as is a water supply to enable me to clean up. My wife, who also has a non-visible disability, has had adverse comments about 'jumping the queue'. She also has had problems when requesting use of accessible changing rooms in shops."



Rachel (Mum) & Jake Allen (Son)

Stoma since birth due to Hirschsprungs Disease

"What worries me as a parent of a child with a stoma is the society we live in where everyone is quick to judge and comment particularly when looking at Jake who appears to have nothing wrong.

Entering accessible changing rooms in shops and toilets, it may appear to some I am just doing so because I have a child and it's easier, believe me when I say, I would give anything not to have to use these toilets.

Having the correct signage would take away the stigma and teach people to respect one another for if you don't know or live with someone with a disability, I understand it can be hard to relate."



Keith Thomas

Stoma since 2012 due to Ulcerative Colitis

"Our aim is to educate the public and change attitudes; hidden disabilities are just that – hidden, not non-existent. We want to open your eyes to what thousands of people go through every day."

To keep up to date with
the campaign give us a follow:

 RespondLtd  RespondLtd

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Product Solution Corner

Pouch leaks

with Community Stoma
Healthcare Assistant, Christine

Welcome to our brand-new series of articles working in conjunction with our team of nurses to focus on topics that you may or may not be familiar with. Whether you are a new ostomate or you have had your stoma for several years, this could really benefit you.

So, in this edition we are going to talk about leaks...

We know leaks can be a common challenge for an ostomate, and recently our Community Stoma Healthcare Assistant Christine helped a patient with a leak problem. Christine's recommendation of using a solidifying agent helped resolve the problem.

Case Study

Her patient underwent bowel surgery, and formation of an ileostomy for bowel cancer in December 2019. He had a history of radiotherapy to his throat and experienced some side effects following his treatment, one of which was a dry mouth. To aid this he frequently had to sip fluids to keep his mouth moist.

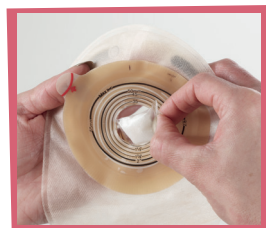


for use in colostomy pouch

During a routine home visit Christine noticed that his stoma output had become very watery and he was experiencing leakages from his pouch. Christine recommended to use ABSORB odour neutralising absorbent gel to help with the watery output. With the help of ABSORB his stoma output massively improved, as did his confidence.

What is ABSORB?

ABSORB is solidifying agent gel that helps prevent leaking by dissolving directly into the stoma bag. The gel will dissolve over time to absorb the extra fluid of the pouch contents. Suitable for both ileostomies and colostomies where the output is fluid, it will help manage noise and leaks. ABSORB will also help with pouch security at night.



for use in ileostomy pouch

How can this help YOU?

- ☒ Does your bag leak?
- ☒ Do you find it difficult and messy when emptying your pouch?
- ☒ Does your stoma pouch leak or explode at night?
- ☒ Are you worried others can smell your output?
- ☒ Do you feel embarrassed when your pouch makes a sloshy noise?

If you have answered yes to ANY of the above, then ABSORB is maybe for you. Get in touch with us today to find out more.



phone

0800 220 300

0800 028 6848 (N.Ireland)



online

respond.co.uk



email

hello@respond.co.uk

Disclaimer: If you are experiencing prolonged and unexpected watery and/ or high output, you may wish to discuss this further with your Stoma Care Nurse.



Sue & Simba's Journey

enquiries@tippytoesbabybank.co.uk
www.facebook.com/TippyToesBB

When my stoma nurse asked if I would write something for the magazine, I thought why on earth me? She said I was an inspiration and should help others?

It made me stop and think about who have I become?

I have had diverticulitis for years and managed it through diet and listening to my body. If I had a flare up, then antibiotics would help.

A stay in hospital with a flare showed I had cancerous cells in my womb, so a full hysterectomy and a Salpingo-Oophorectomy was carried out in December 2018. I got the all clear in February 2019 and thought phew I'm ok, that was a near miss! Let's forget the bad end of 2018 and have a better year! Cruise booked, ready to live again.

But no, my body had different ideas, pain, sickness I knew it was a flare up. After a couple of days on a liquid diet to no avail, off to the doctors I went for antibiotics.

The following morning after a restless night my hubby decided that due to my pain, having a temp and how I looked it was A&E time.

No messing at the hospital, straight in and painkillers given.
My bloods were taken complex regional pain syndrome (CRPS) high, pain, fever, sickness, kept in for IV antibiotics.
What my poor family was going through I can't imagine.

I have 2 sons who wanted to protect their mum, a daughter(Katie who is a student nurse), my own parents who again always make things right , a brother

who has always sorted things for his little sis and a husband who was trying to hold it altogether for everyone whilst inside was breaking, not being able to make this right!

I felt so dreadful that I don't actually remember much of the next 5 days. I slept most of the time only waking to listen to the doctor, I think? I wasn't getting any better, CRPS were still going up, I was being given numerous different antibiotics, having cultures being grown, CT scans, MRIs you name it but I still don't remember it. I vaguely remember a doctor saying we may need to put a drain in, as there was probably an abscess.

I don't have good health, so they were reluctant to operate so were pinning their hopes on the antibiotics working. CRPS still climbing, one doctor told me they were the highest they had seen. To add to this, I had also developed sepsis, and everything was giving up.

As a result, I was told I was going to theatre on the emergency list on the Sunday, I was about 3rd on the list.

I really didn't care by this point I wasn't really with it.

My daughter came in early to see me and with another nurse they started to prepare me for surgery. Through the curtains I heard my hubby arrive, then the doctors voice again, "Mr. Wade we need to take her now!" My CRPs were even higher, so I was now the 1st emergency.

My wash was abandoned, I kissed hubby and daughter goodbye and the next thing I knew I woke up in ICU!

Wow that horrendous pain had gone, but I felt strange drugged up to my eyeballs, monitored, catheterised you name it! But that pain had gone. I put my hand on my stomach and had a huge row of clips and then I felt it! What the heck was that, a crinkly bag!!! What had happened to me? For the next 4 days I was in ICU and again I don't remember much. It was only when I started to come round, I realised what had happened to me.

At my lowest point I was devastated, shocked, confused, angry, every emotion one after the other. All I kept being told was it saved your life you're really lucky!! What, why am I lucky? That's all that went through my mind. What part of lucky did they mean?

I cried and cried and cried, I couldn't look at my bag I wanted it off. My consultant came to see me and again told me how lucky I was, (I realise it now) I looked at him and cried and told him I wish I was dead.

I just did not want this, you go into hospital feeling poorly, they make you better then you go home that's what is meant to happen. No, it didn't feel like that, it felt like I should be leaving my bag behind when I go, I didn't want it and I felt better!

The team of stoma nurses were fantastic, they listened to me, sat with me and changed my bag, showed me different products, got me to talk to other patients with a stoma doing everything they could but I could not accept my stoma. In my eyes it stunk, I would smell, what would people think of me? Everyone would know, and it just wasn't me! I wanted it off, it was horrid and certainly didn't belong to me!

My daughter in between her breaks and shifts would come and empty my bag, change it if needed, support and encourage me to be myself. I cried every time someone looked at it or did anything to it, I felt so embarrassed and different.

My hubby mentioned my holiday! Oh no, I had a cruise booked, no way I could go, not with this!

My hubby promised me I would go as it was what I needed. But I just couldn't, I couldn't even contemplate it.

I was hoping the consultant would say no as it was only 8 weeks post-surgery when we were due to go. My daughter and her partner were coming with us and after a few other rules were put in place my consultant said it would do me the world of good, it was what I needed as long as I could look after my stoma!

That seemed impossible I couldn't even look at it! After a few days I stood in the hospital bathroom with Katie, tears streaming down my face and I emptied it! I was shaking, sick, relieved, disgusted, this was my life!!

After that first go, I kept going to the bathroom and Katie supported me

every empty, or every change. The nurses were trying all sorts for me, they had found me the salts black bags so I couldn't see anything in the bag.

For me to get home and go on the cruise, I had to change it myself, all by myself! I had to get myself into the right frame of mind, through tears and mixed feelings again, I did it! I could do this!

I was discharged home ready to start a new chapter in my life.

After a fantastic cruise even wearing white, It was back home and back to reality! This was my life now, new routines, adjustments, experiments with clothes and my bag!!

My head kept telling me I'd had it long enough now, I was better, so I wanted it gone! My stoma nurse Pauline is a blessing. Always positive, a brilliant listener, non-judgemental, honest and so encouraging.



The tears still came a lot and my feeling of disgust were still there they just wouldn't go.

I had to decide to look at it as a chore that needed doing and had to be done! I needed it to fit in with my daily routine, but what was that? Everything had changed so I decided I needed to be busy, distract myself because my life had become consumed by my stoma!

The family named my stoma 'Simba' from the lion king as it roared occasionally.

Before I became ill, I had started a baby bank, I did this through Facebook asking people for their preloved baby equipment and clothes so I could give to people in need. So, I decided to pick this up again to keep me busy and it WAS going to be successful.

It was hard at first, I was still in pain and discomfort but through the baby bank I discovered lots of other people in pain, just different pain. They were struggling too, but they wanted someone to help make things better, help

change things for them and their families, I felt I could try and help reduce their pain, feelings of helplessness.

So TippyToes BabyBank was founded! I was overwhelmed by the response I had, people who didn't know me or anything about me, wanted to help me support families!!

Donations were coming in, referrals going out, it was working! Health visitors, midwives, social workers started to hear about us and were contacting me for help! This was amazing, I WAS adjusting to life with my bag without knowing it.

TippyToes was growing every day and we were reaching out to more families, other agencies, doctors, family support workers, local councils were hearing about us and referring to us. I had an offer of support from a lady (Sian) who lives local to me and who wanted to help out with the day to day running of the baby bank, she is wonderful, full of inspiration, ideas, and we laugh together, she knows all about me and supports me to continue with my mission.

I no longer have time to feel sorry for myself. I have a purpose again and I can do this, and I am doing it. I CAN stand at someone's door, hand them their baby items and they don't judge me or smell me (as I imagined) but they thank me.

TippyToes is growing and growing and I'm extremely proud of the support we offer to so many families across the Northwest. Sian and I now have a team of volunteers working with us, we have been lent some storage space and we are spreading our catchment area.

We have recently become a registered charity and I could not be prouder of my achievements and the number of families we have supported. We have appeared on TV twice, me, Sian and Simba something I could never imagine happening.

Don't get me wrong, some days I look at Simba and ask it why? Why me? But now even though it can still upset me at times, I like to think I wouldn't be helping others like I am without it! I have so much to look forward too, with Simba always by my side(literally)!!

I cannot thank all the nurses in hospital, Pauline and her team enough, they are guardian angels encouraging me all the way, but most of all, a thank you to the team of surgeons who gave me not only my life, but a purpose in life!

Next hurdle: Mother of the bride outfit!!! Yes!!!!

To find out more about this wonderful Charity please go to:

 TippyToesBB

 @TippyToesBank

Do you have an inspirational story to share with us?

If so, we would love to hear from you.

Get in touch today at marketing@respond.co.uk



Dessert

Scotch pancakes

Cook time 15 minutes,
Serves 4

Ingredients:

- 175g of self raising flour
- 1 tsp baking powder
- 1 egg
- 40g caster sugar
- 100ml milk

Thank you to ostomate
Stephie for all her recipes
in this issue. Go and check
out her website
colitistooostomy.com for
more!



Recipe card

Method:



1. Weigh out the ingredients for the Scotch pancakes.
2. Add them all to a mixing bowl.
3. Whisk it all up into a batter.
4. Melt some coconut oil in a frying pan.
5. Fry them off in batches of 4 – we used a tablespoon measure.
6. Fry for 2 minutes each side or golden brown and set in the middle.
7. Serve it with bananas and chocolate sauce.

Ways we carry on supporting you

24/7
Stoma Helpline
0800 328 4257



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ColostomyUK.org



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support group



ColostomyUK.org
Support booklets



ColostomyUK.org
Back issues of
Tidings support magazine



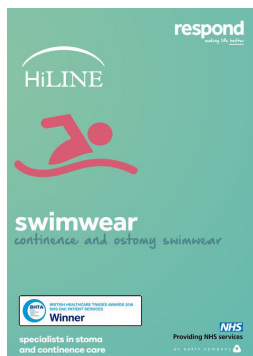
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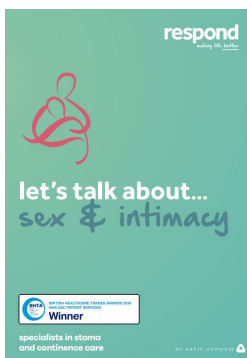


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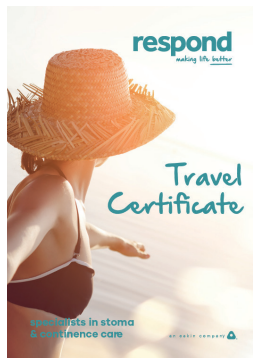
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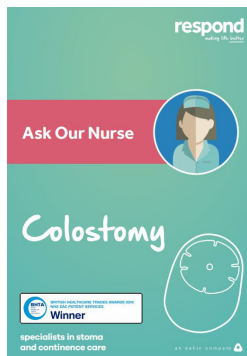
Advice when leaving
hospital

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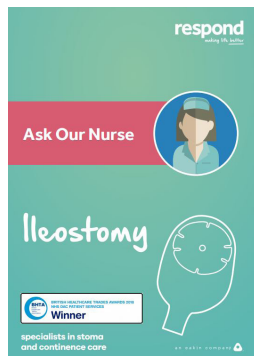

Going on holiday

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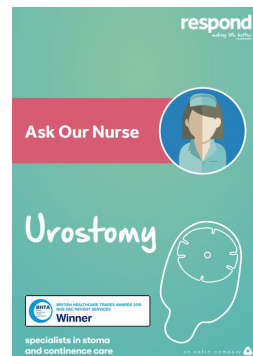
Travel certificates

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your colostomy

☐


Support for managing
your ileostomy

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Support for managing
your urostomy

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useful contacts

Colostomy UK

Enterprise House
95 London Street
Reading
Berkshire
RG1 4QA

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_experiences/ileostomy_and_colostomy_discussions/

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Nottingham
NG2 4NU

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