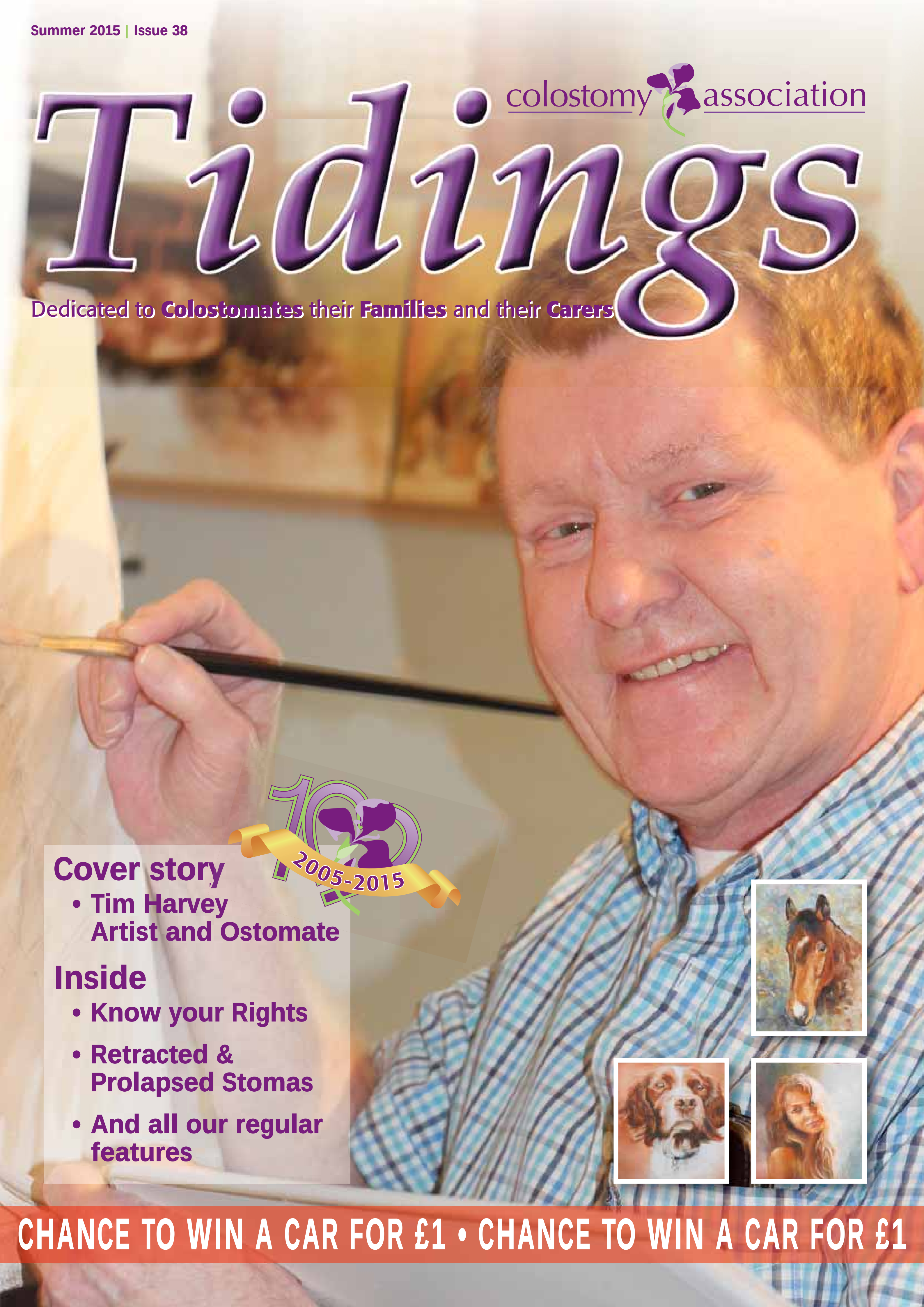
Summer 2015 | Issue 38

colostomy association

Tidings

Dedicated to **Colostomates** their **Families** and their **Carers**



2005-2015

Cover story

- Tim Harvey
  Artist and Ostomate

Inside

- Know your Rights
- Retracted & Prolapsed Stomas
- And all our regular features

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COVER PICTURE

Tim Harvey, busy in his studio with another work of art in the creation. Below right, some of completed works in oil.

How to contact Tidings
By letter write to:

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Via e-mail:
editor@colostomyassociation.org.uk

Advertising Enquiries:
For a media pack and advertising rates.

Contact –
Arvind Anand: 0118 918 0500

dear READERS

When you receive this issue of *Tidings,* there will only be days to go before the Colostomy Association's 10th Anniversary Celebration – the Open Day and Gala Dinner on Saturday 11th and the Fashion Show on the Sunday 12th July. We look forward to meeting all our supporters who are able to join us over the weekend.

The inaugural issue of *Tidings* was published in December 1997, the 30th anniversary of The British Colostomy Association (BCA) previously known as the Colostomy Welfare Group (CWG). At the time I was already a volunteer for BCA and still have a copy of this single page newsletter. With first two, then three issues a year, it increased in size to a 40 page magazine which in 2005 announced the sad news that the BCA was closing down, followed by the glad news that a new charity called simply the **Colostomy Association** had been formed on November 15th 2005. *Tidings* also rose again with a new Issue 1 in the Spring of 2006.

Although CWG was originally formed to support those who had a colostomy formed as a result of cancer, by the time the **Colostomy Association** came into being, a third of colostomies were being formed for reasons other than cancer. In this issue of *Tidings* our Real Life stories reflect the variety of medical conditions that can lead to a stoma.

Both Ian Jackson and Jo Gedik's colostomies were the result of life-saving surgery; in Ian's case a planned operation to remove a cancerous tumour. For Jo it was emergency surgery because of a perforated bowel and abscess due to diverticulitis. Faye Jones was born with a condition called Hirschsprung's disease and back in 2011 told *Tidings* how, after many operations, she opted to have a stoma at the age of 13. Tim Harvey's reason for having a stoma was also to improve his quality of life, after many years of suffering from incontinence.

Not only does the underlying condition which leads to a stoma vary, but also the type of operation to form a stoma can differ. Ian's was called an *Abdomino Perineal Excision of Rectum,* APeR for short, and, as the name suggests, involved the removal of his rectum, so his stoma is permanent. Jo, on the other hand, had a Hartmann's procedure in which the rectum is left intact and, in her second article, Jo writes about her Pathway to a Reversal.

Once we have got used to our stomas, most of us can return to life as it was pre-stoma, but for a few there may be a variety of problems. *Tidings* invite professionals to explain why they happen and the best way to deal with them. In this issue Jennie Burch, a specialist nurse at St Marks hospital, discusses retracted and prolapsed stomas. At our Open Day, Ian Daniel, Consultant Surgeon and President of **Colostomy Association,** will be speaking about parastomal hernias, and will also write about this more common complication of stoma surgery in our next issue of *Tidings.*

Not only do we have different problems, but there are also different solutions and different ways of managing our stomas. On the *From One Ostomate to Another* page, **Colostomy Association** Trustee, Trevor Andrews, explains how he has used the flushable pouch for the last nine years as it solves the disposal problem. Ian and Tim favour the control that irrigation gives them. Noreen feels the same and on the *Irrigation* page considers the various irrigation sleeves available and how one may suit some ostomates, but not others.

We are now on countdown to the **Colostomy Association** Open Day. The editorial team will all be there. Do come up and talk to us; tell us what you like to read about in *Tidings* and give us your suggestions about what we might include in the magazine in the future.

See You There.

Rosemary Brierley
on behalf of **The Tidings Editorial Team**

Email:
editor@colostomyassociation.org.uk

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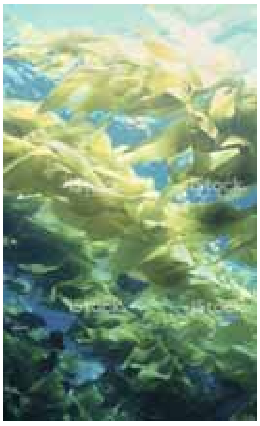

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inside this issue

all your regulars & special features

Updates

From Healthcare Professionals

Living with a Stoma

Real Lives

Focus On

Support

How to get in touch with the Colostomy Association

The Association represents the interests of colostomates and other ostomates. We provide support, reassurance and practical information to anyone who has or is about to have a Colostomy.

How to become a member of the Colostomy Association

Simply contact us by post:
Colostomy Association
Enterprise House, 95 London Street
Reading RG1 4QA

By telephone:
General Enquires: 0118 939 1537

Stoma care queries only:
Freephone Helpline: 0800 328 4257

By E-mail:
cass@colostomyassociation.org.uk

Find us on FACEBOOK:

Find us on Facebook

Join our 'closed' group today simply put Colostomy Association into your FACEBOOK search bar, click on Group and click on 'Ask to join' you will be assured of a warm welcome!

Visit us and **register** at:
www.colostomyassociation.org.uk

Don't delay Donate Online today!

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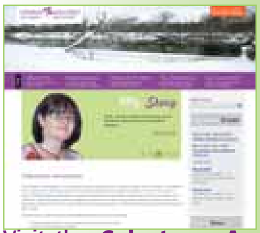
1



Visit the **Colostomy Association website** and **simply click** on the **donate panel** on the **home page.**

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2

Visit the **Just Giving home page** you will see a search panel **'Find a Charity'** type in **Colostomy Association.**

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NURSERY EXPERTS SINCE 1996

Faye Jones was born with Hirschsprung's disease and some of you may remember reading her story in the 2011 winter issue of *Tidings.*

During her childhood Faye had several operations to remove sections of bowel but, as she was still suffering from incontinence at 13 years old, her consultant suggested a colostomy. The operation was complicated due to scar tissue and adhesions from previous operations and it took a long time to recover, but eventually Faye was able to go back to school. In 2011 Faye was 22 years old and had been a colostomate for nine years. She told us how during this time she had travelled to Europe and the USA and had climbed Snowden to raise funds for Alder Hey Children's hospital where she had her surgery.

Four years later Faye takes up the story…

Shortly after my story appeared in *Tidings* I was admitted to hospital with a strangulated parastomal hernia. I just knew it wasn't my usual blockage; there was something really wrong.

The doctors stood at the end of my bed discussing my case. They mentioned septicaemia, so I was pretty scared but it turned out that I was given the antibiotics I needed in time.

On 7th January 2012 I went down to theatre and had emergency surgery during which a foot of small bowel was removed. While I was in hospital I remember Duncan Wells from the **Colostomy Association** contacting me on Facebook; reading his post was wonderful, really uplifting but I just felt too weak to even reply.

It took a good eight months to recover. I was sent home with a wound still wide open and infected. The district nurses came out every day to change the dressing. It was a very long road. I remember my friend visiting and I wanted to walk to the shop which is only about 200 metres away, but I couldn't even make it to the end of the drive. I felt as if I had been in a boxing ring; I was sore and exhausted.

I do still have blockages, far too many of them for my liking. Now as soon as I feel bloated with a heavy feeling in my stomach I take Lactulose. I drink plenty of water and get some exercise by taking the dog for a walk. My best trick is to stand in the shower and spray warm water in circular motions around my abdomen with the shower head. I haven't been hospitalised due to a blockage for three years now.

My ambition was to be paramedic, but in 2013 I realised it was highly unlikely that I would be able to follow this type of career.

CONTINUED ON PAGE 9, COLUMN 1

independence

Innovative and effective accessories for stoma patients, making life that little bit easier...

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Extra-sticky foam adhesive strips for added security

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- The wipe contains a **special non-sting formula** and **DOESN'T** contain alcohol.

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- **Extra moist** tissue which **doesn't dry out quickly**.
- Ingredients help **protect the skin.**
- Will help **reduce skin irritation.**
- The wipe contains a **special non-sting formula** and **DOESN'T** contain alcohol.

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Nottingham, NG6 0BJ

CONTINUED FROM PAGE 7, COLUMN 2

My abdominal wall would never cope with the lifting involved in the job. So I decided to apply for an office job with a local authority. I was offered a post as an apprentice in the social services department, which I loved, but due to sickness and problems with the bag I had to leave after eight months. Then in early 2014 I became a teaching assistant; I was given the opportunity to support a 'Looked after Child', which is why I finally decided that social work was definitely for me.

I am now training to be a social worker. At the moment I think that when I qualify I will go into front–line child protection. However, I am keeping an open mind and may work with people with drug and alcohol problems, or in the youth justice system. So who knows!

Other students don't know I have a stoma because if I need to change my bag I just nip into the toilet and change it just as quick as going for a wee. However, I am quite open about it and would tell the world I have a stoma as I am proud of it. It has made me who I am today and changed my life for the better.

Due to my major surgery and the subsequent infection in 2012, my tummy didn't heal as well as I would have liked. It kind of drooped down on one side but not on the other. I thought it looked awful, so after constant moaning to my surgeon, he finally referred me to plastic surgery in Whiston hospital. In March 2014 I was admitted to have plastic surgery. They performed a miracle! However, as time has gone on I have developed what they call 'dog ears' from where the stitches were pulled a little too tight, I will be going back to the clinic at Whiston hospital soon to discuss the next and final procedure.

In September 2014 I went on holiday to Egypt. We stayed in Sharm el Sheikh where there was a terrific reef for snorkelling and diving. I really enjoyed snorkelling, but unfortunately when I enquired about diving I was told I would have to pay a doctor out there to give me the all clear. That would cost £50 regardless of his answer so I didn't bother. I saw just as much while snorkelling.

While on holiday I plucked up the courage and, for the first time, I wore a bikini. I knew there was more work to be done on my tummy, and to start with I felt conscious of people staring at my bag, but then I decided I didn't care and it felt amazing. It was one of the best things I have done. **Faye Jones**

Faye is now a **Colostomy Association** volunteer and is happy to talk to other young people who live with a stoma, or are facing stoma surgery. Her aim is to raise awareness of Hirschsprung's disease, as well as what it is like to live with a stoma.

Look out for Faye at the **Colostomy Association** 10th Anniversary, where she will be one of our models in the fashion show on Sunday morning.

Hirschsprung's disease is a condition, present from birth, in which nerve cells are absent in part of the bowel. This means that although the bowel can push the motion it can't relax to allow it to move forward. This leads to pain, constipation and blockage.

For more information visit:

Hirschsprung's & Motility Disorders Support Network (HMDSN)

www.hirschsprungs.info

www.nhs.uk/conditions/hirschsprungs-disease

Go Purple for Colostomy Association's CA Awareness Day

This October marks World Ostomy Day – an international day that exists to spread awareness and understanding of life with a stoma across the world.

Here in the UK, we are encouraging supporters to *Go Purple* and help spread awareness of the work and support of the **Colostomy Association,** locally in their own community.

Last year, **Colostomy Association** volunteers donned purple wigs, manned stands and held tea parties to raise funds and awareness of life with a stoma in the UK, as well as promoting the support the **Colostomy Association** provides.

This year's CA Awareness Day is set to be even bigger as we're asking people to follow a *Go Purple* theme. Several businesses have already signed up to serve purple cakes, wear purple t-shirts, put up CA Awareness posters and help raise money for the **Colostomy Association.** However, to make this our biggest CA Awareness Day yet, we need your help too.

There's plenty of ways you can *Go Purple* for the day: you could dye your hair; change your Facebook profile picture to purple; go to work in purple; or, do some purple-themed arts and crafts. The bigger and crazier, the better – by going purple you will be spreading awareness of life with a stoma and will be fighting the poo taboo.

Last year, cabbie – Steve Clark – got himself in the local press by wearing a purple wig and purple top while driving his taxi around Fareham in Hampshire. We would like your most inventive ideas to help spread the word about the **Colostomy Association** and making sure more people with a stoma are able to receive our support.

To take part in this year's CA Awareness Day, to receive a CA Awareness Day pack or for more information, please contact the Colostomy Association Marketing Communications Officer, Niall Norbury. Telephone: **0118 939 1537** or Email: **niall.norbury@colostomyassociation.org.uk**

Pathway to

Ian Jackson, **Colostomy Association** helpline volunteer, Facebook group admin and member of the *Tidings* editorial team, tells us about his journey through bowel cancer.

Looking back I think my journey started very early in 2010 with my first visit to the doctor. I was told it was just a bad back so I had the day off work.

Within a few weeks I was having more of an urgency when going to the toilet and still had a mystery 'back pain' that wasn't in my back. The long walks along the beach and in the countryside that I enjoy were now being affected because of my need to be near a toilet.

Reluctantly, I went back to the doctor again and my problems were diagnosed as piles and I was advised to try cream then, when that didn't work, suppositories. By June I had to stop cycling as it was getting too uncomfortable. My doctor put me on stronger prescription suppositories, but the mystery pain was still there. It seemed around the groin area but a testicular ultrasound scan came back clear. A physiotherapist was the first to put the clues together, asking if I'd lost weight and referring me back to my GP. I was booked in for a colonoscopy. They didn't expect to find anything and it was suggested if it was clear the problems may 'all be in my mind'.

I remember on the day before the colonoscopy in January 2011 we had a training day at work and nobody could understand why I was only sipping at a glass of water and not gorging on the free buffet lunch as normal. At this stage I didn't really share my problems. I took the sedation offered for the colonoscopy so don't remember much about it, but I do remember waking and hearing the nurses telling others around me to get dressed, have a cup of tea and a biscuit and go home. However, the nurse came to me and just said somebody would be there to talk to me in a minute so I was starting to guess something was not right.

My wife, Julie, and I were taken to a small meeting room by a new nurse who told me they would have to wait for the biopsies to confirm it, but they had found something that they believed to be a bowel cancer tumour. The nurse told me she would be my 'key worker' and would be there to help me through all the treatments I was to have, and to be honest she has been there to help me ever since and still is to this day. I really believe if everyone had a key worker as good as her, many more people would have an easier journey through their cancer treatments. It seemed a huge step the next day to go into work and say out loud to my boss: "I have cancer" but once said, all my work colleagues were nothing but supportive. It really is difficult sometimes to share this kind of thing but friends and family can't be supportive unless they know.

The doctor who had performed the colonoscopy confirmed the cancer and was the first to tell me I would most likely need a stoma and it would probably be permanent. I remember nodding as if I knew what he was talking about but the truth is by the time I'd got home I'd even forgotten the word stoma and had to Google bowel cancer. The next meeting was with my surgeon who went though the plans for me: a course of radio/chemotherapy to shrink the tumour; then surgery, hopefully that would sort it out; with the option of a second round of chemo, if needed, at the end. I was also given some leaflets and told not to look on the internet as some of the information on bowel cancer could be misleading. As soon as I got home I hit the internet and decided the two best sites for information were Beating Bowel Cancer and the **Colostomy Association**, and still believe this to be the case.

My radio/chemotherapy was 30 sessions over six weeks. I'd never known anyone that had been through it before, so taking that first chemo tablet was another scary moment. I really didn't know what to expect; it was a big relief that my hair didn't fall out on the spot. The first two weeks went well with very few problems and I managed to continue work as normal. After each session I had a cream egg. I do think setting small goals with little treats does help. After two weeks the urgency to go to the loo was getting too much to go to work or anywhere away from home. A few weeks after treatment, I went back to work while I waited for surgery. During this time I met my stoma nurse who showed me some colostomy bags. I'm not sure what I was expecting, but it wasn't a bag with a hole in it stuck on like a plaster. She also mentioned irrigation, an idea I liked.

My surgeon was keen for his patients to follow the enhanced recovery programme. He explained that I wouldn't have to starve before surgery, in fact would be given energy drinks for the night before and the morning of the operation, as he said he wanted people turning up for the operation as fit as they could be, not starved, dehydrated and scared. For my part I was to try to eat and to get up and move about as soon as I could post op. This suited me well as I'd rather feel I have something to do than just sit back. Strangely I found eating the most difficult, it just didn't seem right to eat post op, but I did make myself and found it was easier to eat standing up

a Colostomy

for the first couple of days. It must have all worked because I was sent home on day five and on day seven when my nurse called to see how I was getting on, I was in the park for a walk. On day ten I had my first trip out to a local coffee shop.

Then I found the CA Facebook group. At that time it was a very small, open group (that means all your friends can see what you post there). I found a huge amount of support in the group; a few in there can never know how much help and encouragement they gave me in those early days (as we'd say on the group: "hugs to all, you know who you are"). Later as the group started to grow, Sarah and Duncan became the group admins and they made it a closed group (nobody outside the group can see what's said). I can honestly say I've made some real friends for life through the group.

Three weeks post op we went on holiday and I had my first bag leak. I started to realise the important part of the seal was where the hole is cut, not the outside edge. I was getting small leaks, ballooning and pancaking and slowly learning how to cope with these but was determined not to let it stop me doing anything.

At my follow up appointment my surgeon dropped the bombshell that he wasn't 100% sure that all the cancer was gone and wanted to go ahead with the second round of chemo. My intention was to go back to work as much as I could through the course of treatment. At first, one session of chemo every two weeks doesn't sound much but when you add in the blood tests and other appointments I was only going in for a few days each cycle and after cycle six had to stop work as the blood results were coming back low and the tiredness was getting too much. At the beginning I had noticed there were 12 bays/seats in the oncology ward and set myself a small challenge to sit in each one for my 12 sessions. I really think that these small goal and little rewards do help when all else seems out of control. I even managed the very rare 13th overcrowding seat by the end. I did suffer a few setbacks where blood levels came back too low. At the time this seemed devastating but now looking back the extra weeks seem nothing. Julie bought me lots of books and movies but the fatigue meant I was unable to read or watch a movie without falling asleep. What did help to pass the days was setting up a camera and trying to photograph the birds in the garden, and the CA Facebook group where I could always find friends and support.

Six week after treatment was complete I was allowed to start irrigation and after a few small mishaps this really worked well giving a lot of control back to me. I didn't always get 24 hours but was now down to one planned bag change a day. For the next year things settled down nicely and the CA Facebook group was getting bigger. We were now having 'meet ups', so I got to travel around and meet other ostomates. Who would have thought having a stoma would bring all these days out?

Then came the "Is that a lump or a small hernia?", that I think many go through. This was confirmed after a CT scan when the nurse said that, as the hernia wasn't giving any problems, it had been decided to leave it for the moment. A year later it was getting bigger and had started to interfere with irrigation as the stoma was getting occluded. So in May 2014 I had my hernia repair. The open surgery inserted a mesh and seemed to go very well. I had to stop irrigation for six weeks, but when I started again it was much more successful and I can honestly say I've not had anything in a bag since then.

Also in 2014 with the CA Facebook group getting bigger I was asked if I would like to help 'admin' the group. Soon after, I also became a **Colostomy Association** Volunteer and Helpliner.

Towards the end of 2014 I started to get an intense pain and swelling under the stoma. At first it was only occasionally, but then more frequently and recently accompanied by severe vomiting. This resulted in an emergency admission to hospital where it was diagnosed as a small hernia that was probably getting strangulated. I am now waiting for the next operation that is planned to be a laparoscopic repair (keyhole surgery).

Throughout this I've had my own little battle to regain my fitness; I often forget I am also five years older and the other side of 50 now. After chemo I was keen to get back to cycling but really struggled with knee pain and then the first hernia. After the hernia operation I tried again and solved the knee problems. I went from strength to strength riding further than I ever had before. Although I'd never been a sports rider before, this year I bought my first road (Racing) bike and decided to sign up for a London–Brighton cycle ride in September 2015. Three of my work friends are going to join me, riding for the **Colostomy Association** in this the 10th anniversary year. The new hernia and upcoming operation is not the best preparation for this but then again what's a challenge, if it's not challenging?

Never Ever Give Up.

Ian
(the grumpy old man
of Facebook)

NEW
Extended Hours

Out-of-hours Nurse Support Line

Amcare Group Nurses are now available to help stoma and rectal irrigation patients with any issues they might have. All our specialist nurses are Care Quality Commission (CQC) registered and hold relevant stoma care qualifications.

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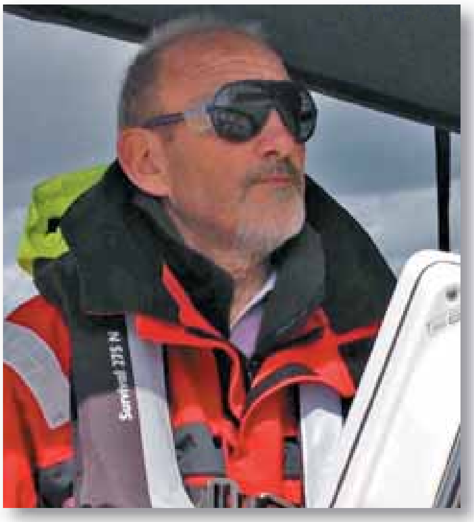
From One Ostomate to Another



The column where ostomates share their experiences and pass on their hints and tips.

Trevor Andrews, Colostomy Association Trustee, writes: You may well know of the two most popular types of pouch, Closed and Drainable; but did you know there is a third type – Flushable? Furthermore, it's a British design.

There has been a considerable amount of discussion on the benefits of irrigation and a reader's letter in *Tidings* Autumn 2014 (T35) supported drainable bags, so I thought it was time someone wrote about flushable bags.

The problem with Closed bags is disposing of the content. Nurses told me I should try and empty the contents into the toilet before disposing of the bag. Family and friends advised I treat it like babies nappies and bin them. Neither option I found attractive from both an environmental perspective and a personal one. After all I was 57 years old, not 5 months.

Then I went to a local **Colostomy Association** Open Day and discovered the answer to my dreams. The Flushable Pouch.

They are simple to use, you put them on like any other pouch. It's the disposal phase that is truly brilliant.

You peel back the outer cover. This, your wipes and the blue bag are the only things to go in the conventional bin. You then peel off the inner pouch, place it in the bowl and flush it away. It feels normal and is much the same as any other person. Furthermore:

- they cost no more than other bags;
- they make it easier to use wherever you go; and
- they are environmentally friendly.

I have been using them for nearly nine years and had only one 'accident' and that was a split bag.

Another benefit for me is that I am into offshore sailing. Now on long hauls, like sailing across the Channel, it can take 15–20 hours. Like any other pouch, flushing it down the toilet isn't an option as marine toilets use a small bore pipe and have macerators to break it down – neither like toilet paper, let alone pouch material even if it is degradable. With flushables I can throw them over the side, as they are biodegradable.

The flushing part of the pouch is largely paper based and the flange is the only part that takes time to degrade.

By the time you read this article, I hope to be making my way down the French coast, in our boat Scallywag enroute to the Mediterranean on a 12 month sailing adventure. The only concern I have is getting deliveries.

I know, whether I be sailing or using a marina toilet, flushables take the ouch out of using a pouch. So ask your supplier to send you a sample, you have nothing to lose.

If you would like to follow our travels then my blog is: www.scallywag.info ■

PICTURES: *FreeSthyle Vie® Flushable*
Used by kind permission of CliniMed®

If you have an experience or anecdote you'd like to share, or hints and tips to pass on to other ostomates e-mail or write to the editorial team:

editor@colostomyassociation.org.uk

Pathway to reversal

I am sitting on a park bench looking up at the blue sky, bright yellow daffodils and the sounds of children playing. I feel happy, deliriously happy, because I finally feel that my journey is coming to an end and YET it feels that life has just begun. Let me explain…

In two weeks’ time, it will be almost three years since my emergency Hartmann’s procedure and *Salpingo Oophorectomy* (surgical removal of one or both ovaries) as a result of perforated diverticulitis. It will be almost three years since I was close to taking my last breath, almost three years since I touched my left side and felt a colostomy bag, almost three years since I lost my hope of ever being a mum and almost three years since I decided that this was not going to manage me – I was going to define my life with a colostomy. I called my stoma ‘Badger’ after a wonderful surgeon at New Cross Hospital in Wolverhampton – and manage ‘Badger’ I did!

Following my Hartmann’s recovery, I returned to a tough Project Management role, travelling to London at the crack of dawn for meetings and frantically running to the disabled toilet in Euston with my radar key poised and my laptop clanging against my colostomy bag. I faced lots of strange stares and comments about being ‘suited and booted’ and, in the eyes of others, obviously not entitled to use the disabled facility. Many a meeting resulted in silence being interrupted by ‘Badger’ gurgling and on occasion operating on volume ten. Working life was a challenge. However, I was determined to keep my positive mentality. I was going to see this through. ‘Seeing it through’ seems a strange statement because I actually didn’t know if my colostomy was for life BUT I dreamt that one day I would be able to have it reversed. We joked in the CA Facebook Group about becoming a Dyson – basically ‘bagless’ and little did family and friends know but I held this dream close to my heart.

I recall going to see the tremendous surgeon ‘Dr Badger’. This was eight months in. “You look great,” he said. “So when do you want this reversal?” I pulled out my A4 pad of sensible notes and bombarded him with questions. “Will it be a one-step surgery or two?”[†] “Will I have an ileostomy?” “Will you open the same scar?” “Will I be incontinent?” “How will you control my pain?” and the list went on… He answered my questions with honesty and I promptly burst into tears and said “I’m just not psychologically ready.” You see, when you have been through a Hartmann’s, on life support and in Critical Care, you feel reluctant to put yourself through what you think will be the same again. I don’t mind saying that I was nothing short of petrified. Dr Badger patted me on the back and said: “Whenever you are ready gal.” I felt useless – why was I so scared? Why was I blubbering?

Fast forward a further three months and I was signing the yellow consent form and listening to Dr Mirza telling me of the potential risks of a Hartmann’s reversal. I love this surgeon. Maybe she doesn’t know but I am entirely grateful to her for my life. She did my emergency surgery and as Dr Badger put it, she would be delighted at ‘plumbing me back together’ and would enjoy it. I felt glad in a way, because when someone saves your life, you have faith in them and their surgical abilities. I felt glad because part of having a successful reversal is that there has to be enough rectal stump to re-join the colon, and in a strange way, I dreamt that she remembered what the inside of me looked like. Of all people, she would certainly know wouldn’t she? To me, Dr Mirza is wonderful. She always has freezing cold hands but is gentle and compassionate and her smile can light a gloomy ward. Even when you feel so ill, you enjoy seeing her and so with a deep breath and my faith in her hands, I agreed…my reversal date was set for 1 November 2013.

The day prior to my reversal, I worked from home – why you ask? Because I took the dreaded bowel preparation. It wasn’t half as bad as I had anticipated – it resulted in a chalky white liquid filtering through. Nothing to write home about.

November 1st 2013 was a Friday. I had to arrive at the ward for 7am. My partner Metin took me, and selfishly, I wouldn’t even let him walk me to the ward. He felt uncomfortable kissing me goodbye on the hospital car park. I was petrified and spoke all the words that a person would say just in case they never pulled through. “I love you.” “If anything happens to me…” I felt as though I was about to walk the plank but with every ounce of courage I had, I walked towards my reversal destiny. I saw Metin wave as I went through the entrance and my heart was pumping.

Once in my rather attractive NHS gown, I was given an enema and Dr Mirza arrived. She looked at me, smiled and said: “You’re first down.” I felt physically sick. I am not sure how long the surgery lasted, but early evening I saw my mum, dad, brother and Metin all smiling at the end of the bed. I was a little dis-orientated but I felt for my colostomy. It had gone and Metin’s thumbs up sign told me it had been successful.

The next few days were pretty tough. My body dislikes morphine and Tramadol and pain control was a big issue. I won’t lie – yes it was painful, yes it hurt to move an inch, yes I had spasms, yes I had wind, yes I vomited, yes I cried… BUT I WAS REVERSED. And even after enduring all of that pain, it was worth every second. I followed all of the tips from the CA Facebook Group – lie on your left side to

expel air, walk and get up as soon as you can, take peppermint water, drink plenty, keep on top of pain relief, eat little and often. Yes, I did it ALL and I hasten to add, I even applied copious amounts of Sudocrem.

I stayed in hospital for two weeks but I am apparently a slow healer. I enjoyed going home but then the spasms hit and the hibernating bowel was really waking up. It was tough. And then the 'giving birth' bit – things were not quite moving as they should. My local GP helped me out with an enema and advised hot baths. And finally... from that day, I continued with recovery. It took months to settle myself down and I really controlled my diet – plenty of salads and lean meats. Nothing processed. Plenty of water and the avoidance of anything that I knew had affected me negatively prior to the operation. Friday night chicken vindaloo was out and plain chicken salad was in!

The stoma healing was the worst. It took five whole months. Again, I learnt that some surgeons glue the wound, some stitch and some leave it open like mine to heal from the inside. My local nurse, Rachel, was a diamond, cleaning and packing it daily. I felt as though it would never 'go' but it did heal and is now a distant memory.

I returned to work in February 2014 after about 12 weeks and soon got back into the swing of things. However, in July 2014 I got a strange, overwhelming feeling – not a bad feeling – a feeling that I was ok and after inhaling for so long, I felt that I wanted to exhale and LIVE. I really can't explain why or what came over me – just that I felt like some ME time. I decided to leave work – a massive step and loss of salary. I have never ever had to depend on a man for financial support but Metin was right by my side. I have just had eight months off and I feel amazing. I have turned down a few jobs because strangely, I feel empowered. I want to do the right job to fit into my life. And that is a first for me!

Finally…yes I am reversed, no I am not incontinent, yes I am stricter with my diet, yes I am on HRT at a young age, yes I get bad days, yes I need Sudocrem but I am so happy and blessed. I would never ever say that I am glad my bowel perforated but in some ways I am thankful that I have been given the chance to view life differently – with a much more positive outlook.

So you see, my journey is finally coming to an end but life is just beginning...and for those of you that are reading and are scared – that's normal. It is uncomfortable but you soon forget.

One last thing, I lost a very good friend who I met via the CA Facebook Group. Her name was Helen Johnson-Isaacs. Helen passed away recently. She had an ileostomy and suffered with childhood cancer. Bizarrely Helen worked for the same company as I did and recognised my name. Unbeknown to me, I had been speaking to her at work and also on CA Facebook Group posts but never clicked it was the same person. Even though Helen could never ever be reversed she was behind me every step of the way. I miss her, and I know that she would just have wanted to live, even with an ileostomy.

More importantly, she made me realise that I am lucky and incredibly blessed to have been able to have a reversal but when I think of Helen and her strength, I also know that I would have lived my life if it had failed. So, with or without a colostomy or ileostomy, cherish your family, friends and breathe the sweet air of each day. Life is so precious. And, if you do get the chance, I wish you luck and hope your outcome is as good as mine.

Helen loved everything pink – RIP my pink lady. I dedicate my story to you. Xxxx

And yes, I am crying as I am typing…

Jo Gedik

[†] Two step surgery is where the bowel is reconnected, but a temporary ileostomy is formed to divert faeces away from the colon to allow the join to heal and avoid the risk of leakage.

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Donations
When sending your donations please don't forget to include your contact details. Thank you!

Fundraising Focus

All of us at the Colostomy Association are constantly surprised and humbled by the various ways our supporters fundraise for us. As an independent Charity, every penny raised helps fund our work supporting ostomates across the UK and raising awareness of life with a stoma.

STOMA AID

Imagine having to make the choice between buying a stoma bag or food for your family. Imagine having to make the choice between spending a week's wages on a stoma bag for your child, or using some rags, a tin can or carrier bag without cost. These choices seem unimaginable here in the UK, but for thousands of ostomates across the world, these are choices they are forced to make each day.

Many ostomates across the world either cannot afford or do not have access to basic stoma care supplies. Meanwhile, in the UK thousands of bags are thrown away each month as they are no longer needed (due to loss of a loved one, allergic reaction or change in stoma size or shape). The **Colostomy Association** has decided to end this injustice – but we need your help.

We have launched an online fundraising campaign for Stoma Aid – a new project which will help to distribute desperately needed stoma supplies to developing countries such as Moldova, Nigeria and Papua New Guinea. To make Stoma Aid a reality we need to raise at least £22,000.

If 75% of our supporters who have never donated to the **Colostomy Association** before gave just £1 each we would immediately raise over £15,000. In many developing countries, £1 is equal to a day's wages and can make a huge difference to someone's life.

We have until the end of July to hit our target or we will be unable to get Stoma Aid off the ground. Visit our website for more information about Stoma Aid and donate anything you can to give thousands of ostomates the kind of life we take for granted here in the UK.

Well done, Liam

After months of grueling training, on Sunday 26th April 2015 Liam Grist ran the long 26 miles of the London Marathon in aid of the Colostomy Association.

Three years ago, Liam's wife underwent surgery for a stoma. Since that day she has received fantastic support from both the **Colostomy Association** and from her husband, Liam. In order to ensure that every ostomate in the UK receives the support she did, Liam kindly ran the London Marathon in aid of the **Colostomy Association.**

Not only did Liam finish the marathon is a fantastic time, he managed to raise an incredible **£2,070** for the **Colostomy Association** – donations coming from family, friends and members of our Facebook group. Liam has definitely earned a thank you from everyone at the **Colostomy Association,** as well as a long break from running!

From Oban to Dundonnell for the Colostomy Association

In October 2013, Paul Hodson was rushed into hospital with severe stomach pain. After three weeks in hospital he underwent surgery for a colostomy. At that time his family were beside themselves with worry and were desperate for information and support.

Late one night, Paul's wife found the **Colostomy Association** number online and gave us a call. She spoke to 'the most lovely lady imaginable' and the help she received made a difference to both Paul and his wife.

To keep **Colostomy Association** services such as our 24–hour helpline running, Paul Hodson is cycling almost 180 miles across the Scottish Highlands in support of the **Colostomy Association** between 22nd and 25th May.

Paul's ride will take him across beautiful Scottish scenery including Oban, Fort William and Loch Ness finishing at Dundonnell the day before his 50th birthday.

Paul is hoping to raise £1,000 for the **Colostomy Association** – so far he has already raised over **£300.** Visit our website to keep up with Paul's training blog and help him reach his target!

CONTINUED ON PAGE 19, COLUMN 1

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CONTINUED FROM PAGE 17, COLUMN 3

Wedding

The closed CA Facebook group has proved to be a fantastic source of information, support and friendship for many people living with a stoma. One person helped by the CA Facebook group was Carol Pell who wanted to raise funds for the Colostomy Association due to the support and help she has received.

In May, Carol Pell became Carol Cooke after marrying her partner, Ray. Rather than asking for wedding gifts, the couple instead asked people to make donations to the **Colostomy Association.** Together, the wedding guests managed to raise **£835** – we're sure you will join us in wishing Carol and Ray a very happy and healthy future together.

Raising cash with goals with Northampton Town FC

A fan of Northampton Town Football Club has come up with an original way of raising money for the Colostomy Association as well as an extra impetus for doing well – for each goal scored, they have donated £2, raising over £134 for the Colostomy Association.

Everyone at the **Colostomy Association** office is rooting for the team and hoping they will be scoring more goals and raising more money for the **Colostomy Association** in the new season.

How your old items are helping the Colostomy Association

In the past few months, the **Colostomy Association** has launched several new ways to help raise money for the charity by donating old and unwanted items.

In March we launched a trial clothing collection service with iCollectClothes. Thanks to the overwhelming response from supporters and the public, our clothing collection service is now set to continue after a trial period with money raised expected to double.

Supporters have been sending in used stamps and in February alone we received a cheque for **£78.84.** Additionally, hundreds of people have been using the freepost envelopes to donate old jewellery and unwanted foreign coins and so far **£830.14** has been raised.

These types of donation cost nothing at all and they are a great way to raise vital funds for the **Colostomy Association** if you are not able to make a physical financial payment. Contact us for more details about how your old unwanted goods can help raise money or visit our website for details.

Special Thanks

- Bird & Bird law firm for their generous donation of **£500** in May.
- Lanhydrock Golf Club in Cornwall raised an incredible **£381.40** at a raffle this Spring.
- Earlier this year, Mike and Pam Tomkin held a joint 75th birthday party and instead of gifts they asked people to make a donation to the **Colostomy Association**. Their 30 guests gave **£175.**

Many thanks to you all, as well as to those not specially mentioned here!

Photo ID Card

The **Colostomy Association** photo ID card is proving very popular as it can be useful if challenged when entering or exiting accessible toilet facilities.

If you would like to apply for a Photo ID card, please complete the form opposite and return it to the **Colostomy Association** for processing with the various enclosures listed below:

- **A copy of your prescription or delivery note as proof of eligibility**
- **Passport photo x 1**
- **Payment – cheque**

Note: Payment can be taken over the telephone if preferred.

Alternatively, the form can be downloaded from our website: **www.colostomyassociation.org.uk**

Please allow 10-14 days for delivery – thank you

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

To obtain a **key or a photo identity card** please **complete the form and declaration.** Make your **cheque payable** to the **Colostomy Association**. Return all required items to:

Enterprise House, 95 London Street,
Reading, Berkshire RG1 4QA

(If you have any queries please contact the admin team at the **Colostomy Association** office via the following methods:
Telephone: **0118 939 1537** or Email: **cass@colostomyassociation.org.uk**)

National Key Scheme - Key and photo ID card purchase

Title:

Name:

Address:

Postcode:

Tel:

Email:

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

Please **tick** as appropriate:

☐ I would like to receive a **key** for a charge of **£3.50** (including postage and packing).

☐ I would also like to receive a **photo ID** card for a charge of **£6.50** (including postage and packing) and enclose a passport photograph.

NOTE: Please send a copy of your prescription/recent delivery note as proof of eligibility and make the cheque payable to: **Colostomy Association**.

Signature of self or carer:

Date: / /2015

Please cut along the dotted line and return to the address on this form - thank you


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RETURNING TO WORK AFTER A STOMA

Jo Moseley
Irwin Mitchell Solicitors

Returning to work after a stoma can be a daunting prospect and you are likely to have many questions. Should your employer make adjustments to your job, or to the facilities that you access? What about if you are looking for work? Do you have to tell any prospective employers about your condition, and if so, when is the best time to do this?

The starting point is to determine whether you have a disability (as defined by law). This is because employers must not discriminate against disabled staff and may have to make reasonable adjustments to enable them to continue to work. These protections also apply to disabled employees who are looking for work.

Some conditions, such as cancer are deemed to be a disability from the point of diagnosis. Therefore if your procedure was linked to cancer, you will be protected by the Equality Act 2010.

You will also be protected if your condition has a substantial and long term adverse effect on your ability to carry out normal day to day activities. Going to the toilet is a normal day to day activity and most people who have had a stoma will therefore be protected.

Does my employer have to make adjustments for me when I return to the workplace?

Yes. If you are "disabled", your employer has a duty to make **reasonable** adjustments to ensure that you can continue to work. This may include making changes to any formal or informal policies, rules, practices or arrangements that adversely affect you, such as being able to take more frequent breaks. It may also include allowing you to return to work gradually (by working fewer hours, or more flexibly) until you regain your strength. Similarly, the duty may extend to making changes to the employer's premises (including toilet facilities) or making available certain aids (such as disposal facilities for your pouch).

What is reasonable?

Your employer will only have to make changes to the extent that they are reasonable. This can be difficult to judge and will to some extent depend upon the size and resources of the employer (larger employers will be expected to do more than smaller ones), but relevant factors include how easy it is to make the change and how expensive it is. The cost of any adjustment should be borne by your employer – not you.

Do you have to tell your employer what adjustments you need?

Technically, it is the responsibility of your employer to make any adjustments that are reasonable – you do not have to suggest them. However, it is often helpful to discuss this with your employer in advance of your planned return.

There are certain facilities that you are likely to need, for example, the use of a disabled toilet where wash hand basins are in the same cubicle. Your employer is also likely to want to understand the facilities you need to dispose of your stoma bag to enable it to manage any risk in respect of health and safety for you and your colleagues.

It is often helpful to have an open dialogue with your employer to keep them updated about whether the existing adjustments are working and whether you need anything further.

Should I mention my stoma at interview?

No. Employers should not ask candidates about their health at interview stage unless such questions are necessary for them to determine whether you are capable of doing the job or if they need to make any reasonable adjustments for the interview itself.

If you are offered the job, you could then mention the stoma, either in discussion with your new employer, or by including this information in a health questionnaire response. Your employer is then likely to contact you to ask what facilities you need in order that they can look at making any reasonable adjustments.

Please note – your prospective employer only has to make reasonable adjustments if they know about your condition. If you don't tell them, they don't have to do anything.

What should I do if my offer of employment is withdrawn after I tell them about my stoma?

You may be able to bring a claim in the Employment Tribunal for discrimination and seek compensation. You must take action within three months of the act of discrimination by initially contacting Advisory, Conciliation and Arbitration Service (ACAS) – to go through a process known as early conciliation – and if this is unsuccessful, issuing a claim.

You will need to take advice before doing so as discrimination claims are complicated and the time limits that apply are strict and can be difficult to understand.

Should I tell my colleagues about my stoma?

Only if you want to. Your employer should keep any information about your stoma confidential and should only disclose information about it to others, with your permission. They may ask your permission to let your line manager know about it and it would be sensible to agree to this. However, it is entirely up to you to decide if you want to and when to tell colleagues.

Jo Moseley is a professional support lawyer at Irwin Mitchell solicitors specialising in employment law. ■

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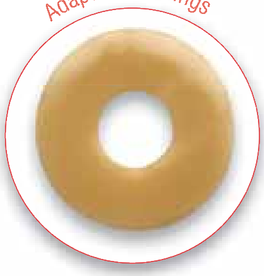

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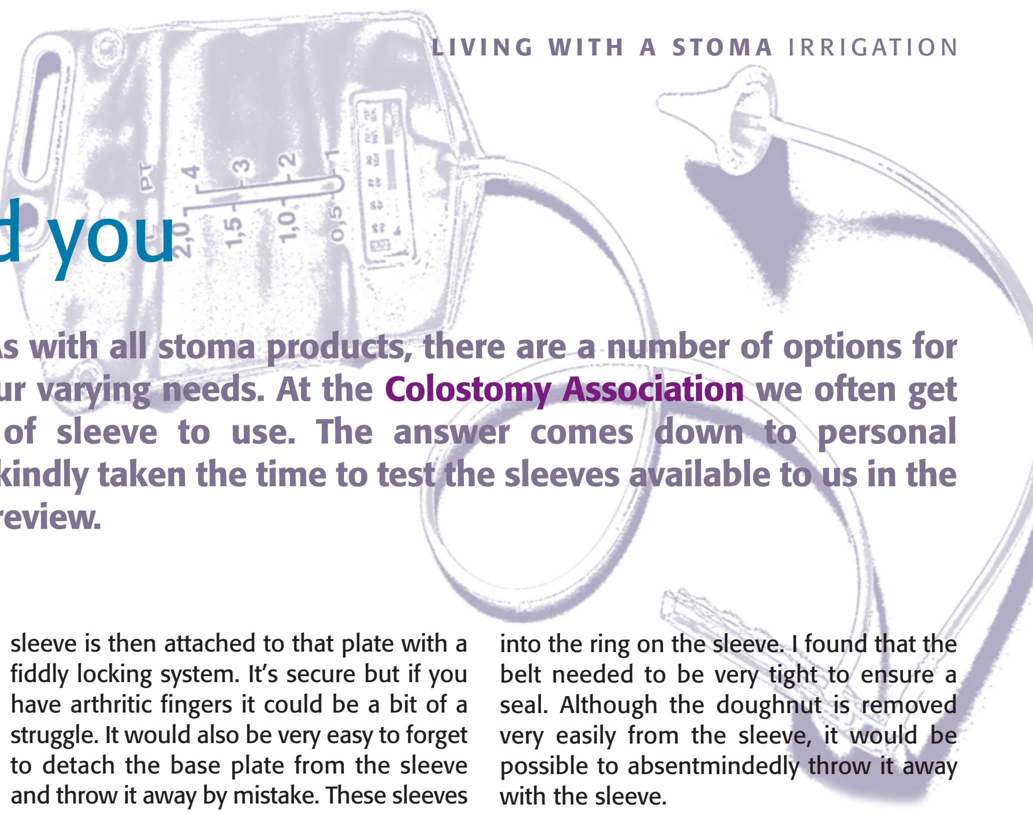

Irrigation and you

Sarah Squire, Trustee writes: As with all stoma products, there are a number of options for irrigation equipment to suit our varying needs. At the **Colostomy Association** we often get questions about what kind of sleeve to use. The answer comes down to personal requirements but Noreen has kindly taken the time to test the sleeves available to us in the UK and gives us her personal review.

Noreen writes: Irrigation is a great method of faecal control for those with medically suitable colostomies.

The water bags, flow regulators and cones of the various manufacturers all have their pros and cons but the irrigation sleeves, the plastic tubes which take the faecal output from the stoma to the toilet, have more differences. I hope my assessment of them may be helpful.

I must stress at the outset that this is my personal opinion. My advice to you is to do as I did, contact the manufacturers directly and ask for samples. They will probably want to send you three samples; ask them very nicely for ten. In my opinion you cannot get a good feel for any stoma product unless you can try it exclusively for something over a week.

The first and most obvious difference between sleeves is the method by which they attach to the body. Some are adhesive and some are connected to a belt round the body. Try them both.

Braun make only adhesive sleeves which attach directly to the skin. If you prefer, they can also be stuck onto a belted Braun irrigation base plate. They are the most transparent of all the sleeves.

Transparency is an advantage when you start irrigating as you can see the stoma and cone through the plastic and aiming the cone in the correct direction is therefore easier. These sleeves have freezer bag closures along the top which are useful. They are long enough to reach the toilet if you want to sit comfortably on a chair and not on the loo. They have the most plastic above the stoma hole which is helpful when you are learning to irrigate as you are less likely to splash water out of the top of the sleeve when introducing it.

Braun sleeves also have the biggest top opening making cone entry very easy.

Coloplast make only belted sleeves. The belt is attached to a pressure plate and the sleeve is then attached to that plate with a fiddly locking system. It's secure but if you have arthritic fingers it could be a bit of a struggle. It would also be very easy to forget to detach the base plate from the sleeve and throw it away by mistake. These sleeves can also be attached to a Coloplast base plate so if you use that system these sleeves could be ideal for you.

Coloplast sleeves are slightly less transparent than Braun ones. They are long enough for you to sit away from the toilet. They have freezer bag closures along the top but not quite as much plastic above the stoma hole. They are also slightly narrower at the top but cone entry is still easy.

Hollister also make only belted sleeves. The belt attaches directly to the sleeve and there are no other bits and pieces so they are the easiest of the belted sleeves to use. They have freezer bag closures along the top. They are, however, very short and I had to sit on the toilet when irrigating. They are also the least transparent of all the sleeves.

However, this different type of plastic cleans much more easily by running water through it after irrigating, an advantage if you really want to reuse the sleeve, although they are prescribed as single use. Two other disadvantages are that they have very little plastic above the stoma hole and the top of the sleeve is the narrowest making cone entry the most difficult of all the sleeves.

As far as I can ascertain the only manufacturer which supplies both types of sleeve in this country is Dansac. With the belted type the belt attaches directly to the sleeve. A silicone doughnut is then fitted into the ring on the sleeve. I found that the belt needed to be very tight to ensure a seal. Although the doughnut is removed very easily from the sleeve, it would be possible to absentmindedly throw it away with the sleeve.

Dansac adhesive sleeves attach directly to the skin so work well.

Dansac sleeves are semi-transparent and are long enough to reach the toilet if you want to sit on a chair. They do not have freezer bag closures along the top. Dansac do, however, provide wonderful little orange clothes pegs with which to seal the top and bottom of the sleeve. These clothes pegs are shorter than normal ones so do not dig into your tummy if you bend down. They are also very strong. I love these clothes pegs.

Apart from transparency, Dansac sleeves do have two other minor disadvantages. They do not have a lot of plastic above the stoma hole and they are also narrower at the top than Coloplast and Braun sleeves making cone entry slightly more difficult.

I must emphasise again that these are my personal opinions. I use Coloplast belted sleeves and Braun adhesive ones. If you watch the **Colostomy Association** DVD of Judy irrigating you will see that she is happily using Dansac products. The YouTube video of Brian in New Zealand shows him using a Hollister sleeve and he is obviously perfectly comfortable sitting on the loo to irrigate. As with everything else it's an individual thing. Try all the sleeves and find out which products work best for you. ■

Irrigation is a method of colostomy management which involves using specialist equipment to introduce warm water into the bowel via the stoma. The water causes muscular contractions (peristalsis) within the bowel which in turn cause expulsion of its contents. Many Ostomates prefer this method of colostomy management as it gives them a sense of control. If you feel you would like to try irrigation you should first contact your stoma nurse to see if you are a suitable candidate. If you get the go ahead they will then arrange a time to teach you. Also have a look at the **Colostomy Association** website for more information on irrigation and how to purchase the *Irrigation and you DVD*.


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Enhanced Recovery Nurse Facilitator
St Marks Hospital, Middlesex

There are a number of complications that can occur with people who have a stoma. These can include a prolapsed stoma and a retracted stoma. Jennie Burch is an Enhanced recovery nurse facilitator at St Marks Hospital, Middlesex and she explores these two topics so Tidings readers can understand how to care for their retracted or prolapsed stoma if it should occur.

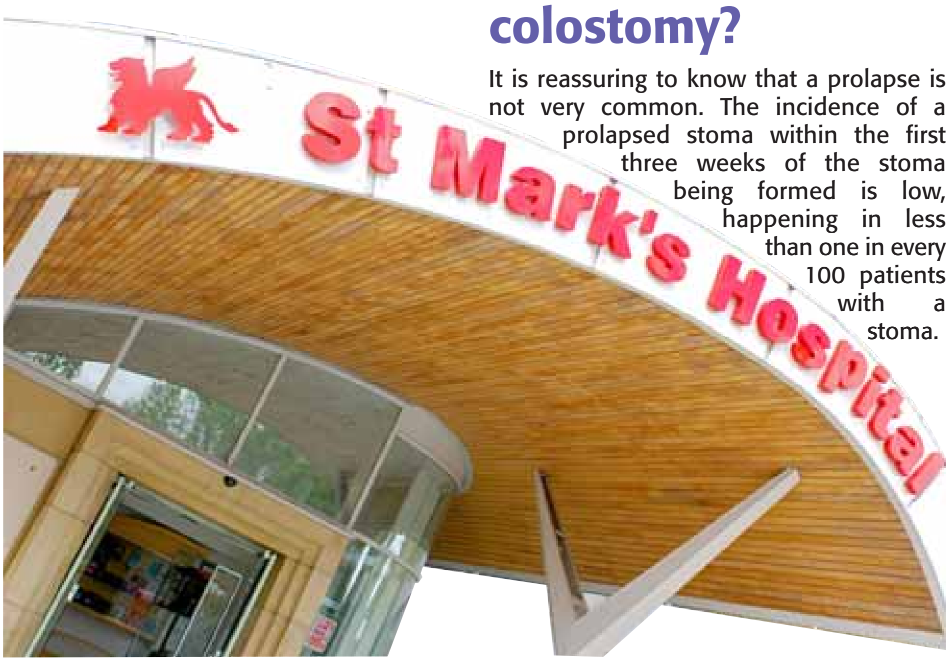
Jennie Burch writes:

What is a prolapsed colostomy?

A prolapsed colostomy is a colostomy that has grown longer, telescoping out of the body; sometimes quite suddenly. People with a transverse colostomy have more risk of having a prolapsed stoma. The colostomy will look larger and may even completely fill the stoma bag.

How common is a prolapsed colostomy?

It is reassuring to know that a prolapse is not very common. The incidence of a prolapsed stoma within the first three weeks of the stoma being formed is low, happening in less than one in every 100 patients with a stoma.



In the longer term, there is more chance of a stoma prolapsing. About one in four people with a loop transverse colostomy will experience a prolapse. For people with an end colostomy this risk is much less with about three in every 100 patients reporting a prolapse.

Why does a prolapse occur?

There may be no reason for the prolapse to happen. Alternatively it may be a result of increased abdominal pressure or pregnancy.

How to look after a prolapsed stoma

It is advisable to book an urgent appointment with the stoma specialist nurse the first time that a prolapse occurs. At this meeting the nurse can assess the stoma, the skin around the stoma and the appliance that is being used. Sometimes the appliance size may need to be changed at this visit. If the prolapse is very long a larger bag may be necessary to contain the prolapsed stoma and the faeces.

One possible treatment for a prolapsed stoma is the manipulation of the stoma back inside the body. Do not attempt this without explanation and instruction from a stoma specialist nurse or a doctor. Manipulation of the prolapsed colostomy back inside the body can be performed with the help of a cold compress or sugar.

CONTINUED ON PAGE 26, COLUMN 1

Prolapse & retraction

CONTINUED FROM PAGE 25, COLUMN 3

Using sugar can be messy and should only be used if assessed as appropriate by a health care professional.

Prolapsed colostomy

If a prolapse will not stay inside the body, you should check it regularly at each bag change for:

- A change in colour – becoming darker or black requires urgent medical attention.
- Bleeding – this may occur as the bowel is now larger and thus more at risk of being knocked accidentally. If there is bleeding a gentle pressure will usually stop the blood flow. If bleeding will not stop then urgent medical attention is necessary.
- Lack of faeces and flatus from the colostomy. Call the stoma specialist for advice. Explain how long the stoma hasn't worked for, if this has happened before, if your stomach seems swollen/distended, if your stoma has changed colour or if you are experiencing any abdominal pain.

A trick for looking after a colostomy that is 'normal' in size sometimes and that is prolapsed at other times is to 'feather' the inner edge of the flange. This is achieved by making small cuts into the inner edge of the appliance adhesive before it is adhered to the abdominal wall.

In other situations the prolapse may disappear back into the body during the night and in this case a stoma shield can be used. The shield is a small, half egg shaped, plastic cover used over the colostomy bag/appliance. The shield is held in place by a small elastic belt and helps to prevent the prolapse from occurring during the day.

If there are problems with the colostomy prolapse being excessively large or other issues occurring such as bleeding, an operation may be necessary. Generally people can manage a prolapsed colostomy without surgery.

What is a retracted colostomy?

A colostomy can be considered retracted if it is below the level of the abdominal wall. When forming a colostomy it is now thought that it should to be slightly raised above the abdominal wall by about 10mm. Research has suggested that a colostomy that is raised about 10mm tends to have fewer problems compared to ones formed shorter.

The incidence of any type of stoma being retracted stoma within the first three weeks of the stoma being formed is about 14%. This means that about 1 in every 8 people with a stoma will have a retracted stoma. In the longer term there are fewer reports of people with a colostomy having a retracted colostomy; up to 6% of people.

Retracted colostomy

A retracted colostomy might result in faeces creeping under the adhesive part of the stoma flange/baseplate. This can result in the skin becoming sore or the appliance leaking.

Why does a colostomy retract?

Sometimes it is difficult for surgeons to form a colostomy for a variety of reasons. This may result in tension on the stoma that pulls it back into the abdomen.

Another uncommon reason that the stoma might become retracted is because of problems soon after the operation. Problems include the skin and the stoma becoming detached. Other terms that can be used to describe this occurrence include stoma separation, mucocutaneous separation or mucosal separation. Once healing has occurred the stoma might become retracted.

Also if the stoma was dark or necrotic after the operation this may also result in the stoma becoming retracted. Although luckily, this is quite a rare occurrence.

Weight gain after an operation can also result in the colostomy becoming retracted. This is because the stoma remains in the same place but the abdominal wall expands around it.

How to look after a retracted stoma

If the stoma is retracted it should be assessed by the stoma specialist nurse. There are a number of stoma products that can be tried, including a stoma seal, a convex appliance or a stoma belt. For some people losing weight may be a solution.

A stoma seal can also be called a washer. There are many different types. Some are stretched to fit and others are made in different sizes. The stoma seal adds a little extra thickness directly around the stoma and under the appliance. This thickened area helps the appliance to stick better to the abdominal wall.

A convex appliance is shaped as a small dome that pushes into the abdominal wall. This pushes the skin around the stoma in slightly, which pushes the retracted colostomy out slightly. This helps to improve the adhesion of the appliance and prevent it from leaking. Convex appliances need to be used with caution as the pressure from the dome shape can cause bruising or in extreme situations ulceration. Bruising or ulceration is rare but at each appliance change the skin should be checked for any signs of damage. If ulcers occur an urgent review by the stoma specialist nurse is necessary.

A stoma belt can be used in conjunction with a stoma appliance. It is a thin elastic belt that is clipped to the edge of the appliance and holds the appliance more securely to the abdominal wall. The belt should be as tight as undergarments. The belt should be worn level with the stoma appliance and not on the waist. Often the stoma belt is used in conjunction with a convex appliance for increased security. The belt can be hand washed and reused as necessary.

If assessed to be necessary a surgical revision of the retracted colostomy may be needed. However for most people this is not required.

Conclusion

To summarise, although a prolapsed or a retracted colostomy is in the vast majority of cases not serious it does require review when it occurs. Sometimes surgery is necessary but often care is possible without the need for an operation in most people with either a prolapsed or a retracted colostomy.

Jennie Burch

Where does peace of mind come from?

Pelican Convex bags are designed for flush or retracted stomas ensuring a perfect fit.

Flexible with a soft, secure skin protector, giving you peace of mind for the day ahead.

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It's your choice

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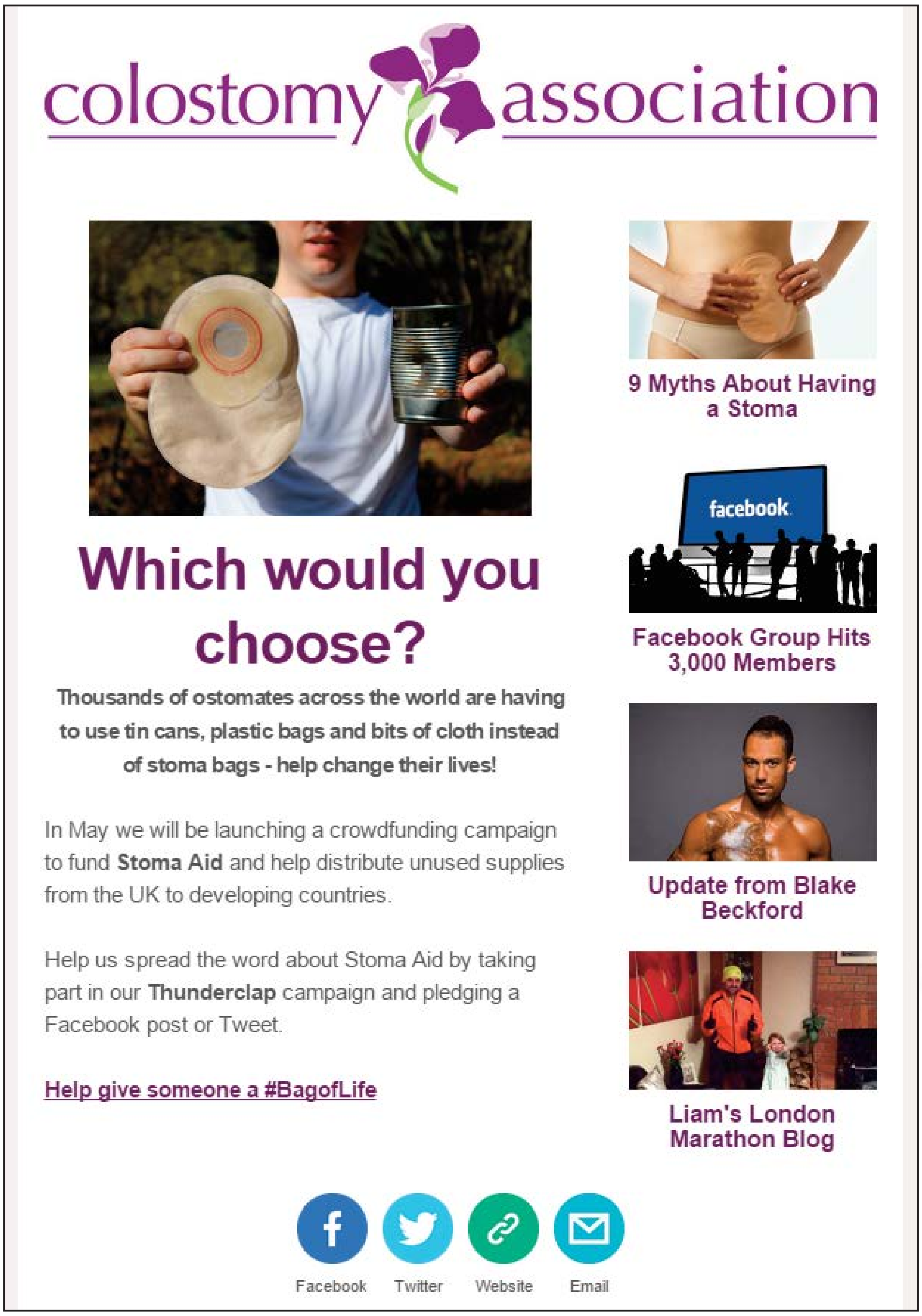
HEALTHCARE

Can't wait until the next issue of *Tidings?*

There is now another way to keep up to date with the Colostomy Association via our new E-Newsletter.

Sent off via email at the end of each month, the **Colostomy Association** newsletter contains all the latest news for ostomates in the UK.

Each month we handpick the best news stories from the **Colostomy Association** website and across the Internet to make sure our supporters are kept up to date with what is happening with our charity as well as in the wider stoma community.



Which would you choose?

Thousands of ostomates across the world are having to use tin cans, plastic bags and bits of cloth instead of stoma bags - help change their lives!

In May we will be launching a crowdfunding campaign to fund **Stoma Aid** and help distribute unused supplies from the UK to developing countries.

Help us spread the word about Stoma Aid by taking part in our **Thunderclap** campaign and pledging a Facebook post or Tweet.

Help give someone a #BagofLife

9 Myths About Having a Stoma

Facebook Group Hits 3,000 Members

Update from Blake Beckford

Liam's London Marathon Blog

Each newsletter contains a brief update of the latest headlines from the **Colostomy Association** with a mix of fundraising updates, blog entries, campaign news as well as the biggest stoma stories in the news each month.

Our E-Newsletter is a bite-sized way to enjoy the latest information from the **Colostomy Association.**

Our E-Newsletter was launched at the beginning of this year and we have already had hundreds of people sign up to this new way to stay engaged with the **Colostomy Association.** The newsletter is tailored to fit our audience so if you feel there is something we should be including then feel free to get in touch.

If you'd like to receive monthly email updates from the **Colostomy Association** then signing up is simple.

Simply follow the link below, fill in your name, post-code and type of stoma and you will receive the latest news from the office in your inbox at the end of each month.

We will make sure your details are kept confidential and that you will only receive one monthly update from us – no annoying spam messages or emails filling up your inbox.

Signup via the following link to make sure you stay in the loop about what is happening with the **Colostomy Association:**
eepurl.com/baYDq1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6

Update on stoma care products and services

Tidings **is always interested to learn about new stoma care products and services from manufacturers and suppliers.** If you have found **a stoma care product** or **service beneficial to 'living with a colostomy' please let *Tidings* know. YOUR findings could make ALL the difference to others.**

NEW Lift Plus 360 and Lift Plus 360 Citrus

Non-sting adhesive removers

opus healthcare
A Division of Alliance Pharmaceuticals Ltd

Lift Plus 360 helps to break down the adhesive bonds that the flanges and pouches form with your skin to make their removal simple and less painful.

Presented in a spray, which is ideal for the instant removal of pouches and flanges. Lift Plus 360 uses the latest bag on valve technology so the spray can be applied from any angle (360 degrees), offering greater reliability and is not cold on the skin.

For a free sample of **Lift Plus 360** or **Lift Plus 360 Citrus**:

– call: **0800 458 7605**

– visit: **opus-healthcare.co.uk**

New Varimate Curved Retention Strips

PEAK MEDICAL

These extra thin hydrocolloid curved retention strips provide additional security and peace of mind when needed. Easy to apply, skin friendly, breathable, yet water resistant – ideal when swimming and bathing!

Now available on prescription from your GP and can be obtained from your usual supplier.

For more information about Peak Medical's new **Varimate Curved Retention Strips** simply call Freephone **0800 652 0424** or email:

info@peakmedical.co.uk and quote **M86** to receive your **FREE samples.**

Visit Peak Medical's website: **www.peakmedical.co.uk** for more information.

Market leader launches NEW flushable Appeel and LBF wipes

CliniMed®'s Appeel® and LBF® Hydrosolve™ Flushable Wipes are the first and only medical adhesive remover and barrier film wipes suitable for flushing down the toilet, giving you freedom and confidence to flush and go.

The new wipes use a patented dispersible material, which breaks down completely on contact with water in the toilet bowl so you don't have to worry about finding a bin.

Appeel and LBF Hydrosolve Flushable Wipes have all the benefits you would expect from Appeel Medical Adhesive Remover and LBF No Sting Barrier Film with the added convenience of quick and easy disposal.

For more information or to request free samples please contact:

CliniMed Careline:	**0800 036 0100** **enquiries@clinimed.co.uk**
Website	**www.clinimed.co.uk/Hydrosolve.aspx**

PID 1599

New Aura® 2 two-piece with Manuka honey

Complementing the Aura® one–piece range with Manuka honey, CliniMed has launched a brand new range of two–piece products, Aura® 2 with Manuka honey.

The inclusion of medical grade Manuka honey to the skin friendly Hyperflex® hydrocolloid flange may help to promote healthy skin around the stoma. This together with a dual secure connection, you can rely on, makes this CliniMed's kindest range of two–piece pouches yet.

In addition to the potential benefits of Manuka honey and dual secure connection, the new Aura®2 two–piece range offers new and enhanced features including; new improved carbon filters, easy grip release tab and a super soft backing.

Aura®2 with Manuka honey is available in a wide range of sizes for closed, drainable and urostomy, with both flat or convexity flange options.

For further details please call the CliniMed team on: **0800 036 0100**

TWO PIECE Aura®2
with Manuka honey

PID 1643

NEW Adapt Slim Barrier Rings from Hollister

The newest addition to the full range of Adapt barrier rings from Hollister, the Adapt slim barrier ring, delivers the same convenient features of the other Adapt barrier rings – at around half the thickness of the standard flat ring.

The Adapt slim barrier ring:

- Measures just 2.30 mm thick
- Is designed to be easier to stretch, mould and shape
- Offers a lower profile and a less bulky alternative
- Is packaged in clearly labelled individual transparent trays for easy storage at home and when out and about
- Available on prescription 1st August

For ostomists who need a ring to improve their pouch fit we can now offer standard, slim, convex and oval adapt rings in several sizes, as no two individuals are the same.

To request FREE samples of any of the rings, please contact Hollister Customer Services on **0800 521 377** or email **samples.uk@hollister.com**

The most popular Adapt barrier ring – now 50% thinner

Hollister *essentials*
The options you need. The expertise you want.

New from Hollister: Adapt Medical Adhesive Remover Spray

To help make skin barrier or pouch removal an easier process Hollister have improved the formulation of their adhesive remover spray to make it more effective

- Alcohol free, silicone based formulation, no-sting
- Bag-in-Can technology
- Up to 99% emptying - minimal waste
- Spray from any angle - 360 degree dispensing
- Quieter than traditional aerosols
- Even and controlled spraying
- More discrete size and can design
- Available on prescription 1st August

To request FREE samples of any of the rings, please contact Hollister Customer Services on **0800 521 377** or email **samples.uk@hollister.com**

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AMI/Suportx are now stocking and offering the Corsinel range of premium support wear.

We offer a prompt delivery service as well as a free fitting service.

For more info see our advert on page 16 or call: **0800 917 9584** or visit: **www.suportx.co.uk**

Double Support & Hernia Belt

SASH Medical Ltd have extended their range of **Stoma Hernia Support Belts** and **Security & Leakage Belts** and can now offer a **Double Support & Hernia Belt** for Ostomists who have two stomas, one on either side of their stomach.

The two restraining flanges have holes cut into them to fit the pouches used by the ostomist and are laced together to give adjustment for the measurement between the stomas.

The laced flanges are secured around the waist with a 50mm (2") webbing and adjustable to the waist measurement by Velcro fastening.

As with the Sash Hernia and the Security & Leakage belts, the hole cut into the flange allows the body waste to drop directly into the bag section of the pouch and helps eliminate waste being squeezed past the body and the pouch adhesive.

For further details please phone us on our Freephone number
0800 389 3111

Another first for the *Tidings* Privileges Programme

Cheeky Rascals, distributors of **Korbell disposal systems** have joined our *Privileges Programme* with a **20%** discount for *Tidings* readers.

Available in three sizes – odour free and hands–free operation. See advert on page **6.** Available to order online at **cheekyrascals.co.uk** or by calling Customer Services on **01730 895761**

In our last edition, The Biggest Little Gift Company launched Poo–Pourri, the 'before you go toilet spray' with a special offer exclusively for *Tidings* readers. The product has been so well received by the readership with over 800 bottles sold that the Company have extended the offer.

This is not a chemical cover up and the product really works. You can save up to **24%** off their already low prices; full details of the offer are on page **18.**

For more information, Email:
orders@biggestlittlegiftco.com
alternatively call **01925 453 031** or visit
www.biggestlittlegiftco.com

but I CAN'T TALK ABOUT IT

Tim Harvey and top–left, with one of his oil paintings of, guess who?!

Overactive Bladder Syndrome and Faecal Incontinence

This article is based around the experience of one of our patients and highlights the emotional and often traumatic journey of those with bladder and bowel dysfunction.

Tim Harvey is a 55 year old man with a very active lifestyle. He currently works as a highway officer in one of the busiest stretches of the M25 and is often first on the scene of many incidents and accidents. Tim lives with his devoted wife Carol and they have one son.

Tim is also an amazing portrait artist which is one of his many hobbies. Tim describes his quality of life now as "very good" but this hasn't always been the case as there have been many dark times when Tim questioned whether he wanted to live at all.

Tim remembers bedwetting as a young child and being made to feel dirty, often being made to wear a nappy once home from school. As Tim got older the frequency of his bedwetting increased so that at the age of 20 he was afraid to go to sleep, drinking copious amounts of coffee to stay awake at work even though he was aware that coffee exacerbated the problem.

It is hard to comprehend, but nocturnal incontinence continued for 10 years and to make matters worse Tim started to become incontinent of urine during the daytime also.

He reached an all-time low when on one particular day he experienced five 'accidents', including once in front of a member of the public on the motorway. By this time Tim was married and working as a highway traffic officer.

There was obviously an underlying medical cause for his symptoms. One has to wonder whether Tim's shame at bedwetting as a child stopped him seeking help sooner but after three attempts Tim finally found a female GP who understood and a referral was made to a Urology Consultant.

Tim recalls:

> *"Toilet training was somewhat delayed due to breaking my leg at eight months old. My parents split up when I was three so that might have had an impact as well.*
>
> *"Bedwetting was definitely an issue for me, and my parents were unable to tolerate it and I was constantly made to feel dirty and was punished regularly – I believe this had a long term effect on how I dealt with bladder and bowel problems throughout my life.*
>
> *"I would lie awake and try not to sleep by digging my finger nails into my hand.*
>
> *"During the day I was suffering with urgency and spent my life 'toilet mapping'. This went on for at least 10 years, not sleeping properly drinking too much coffee to stay awake which obviously made things worse."*

Tim was diagnosed with Overactive Bladder Syndrome (OBS) and underwent *hydrodistension* to increase bladder capacity. This involved stretching the bladder using water under pressure and it worked for approximately five to six years (although Tim was still incontinent two or three times a day). After trialling a barrage of medication a further hydrodistension was carried out but all was not well. Tim experienced episodes of urine retention, and failed his trial without a catheter; he had 20 indwelling catheters in a six month period with recurrent urinary tract infections, pain, and a scarred and ghost urethra. Tim had four months off work and laser treatment to remove scar tissue which left him completely incontinent of urine.

Tim recalls:

> *"As probably the only way forward I was offered laser treatment but*

warned I would be left with little or no bladder control – it was the option I went for and have not regretted it since, and that was 2009. To this day I wear a Conveen and leg bag and an incontinence pad. This may not be the answer for some people but for me this is 100% better than suffering the physical and psychological pain I had experienced."

The worst was yet to come…

As if Tim hadn't suffered enough, he had surgery for a nasty perianal abscess and his anal sphincters were damaged as a result. Over a period of seven years gradually Tim started to suffer with faecal incontinence.

Tim explains how this impacted upon his life:

> *"At 43, I had an extensive perianal abscess. Unfortunately my anal sphincters were damaged as a result of surgery to this. I was warned I could end up with a colostomy but was pleased there was no need at that time. In the same year I had a heart attack and was treated at the Royal Brompton hospital.*
>
> *"The following year I started to have bowel problems, urgency and leakage and some foods like fibre would go straight through me. My father had just been diagnosed with bowel cancer, so I was particularly concerned. I was referred to a specialist and a large amount of scarring and damage to my anal sphincters was found.*
>
> *"The emotional effects on me were huge as my bowel control became worse and revived the childhood memories of being dirty and ashamed and having to use a nappy/incontinence pad 24/7. The constant stress caused my hair to fall out and depression to take hold. I was doubly incontinent at night which was just horrendous and un-describable waking up like that every morning. Thoughts of suicide were never far away."*

Treatments – the long haul

> *"The specialist help I received was good but it takes time to try different treatments to find out if they work or not. Over a period of three years I went from trying anal plugs and medication to rectal irrigation which did actually work for about eight months. However, eventually I had to decide on a better quality of life and started to ask about a colostomy. I was advised against it because of the risks, and even just prior to sedation I was asked if I really wanted to go through with the operation. This was in October 2013."*

Once Tim had been referred to Wexham Park we were able to provide psychological support in a safe environment in which to talk about how he felt and discuss options of improving Tim's quality of life.

We were able to offer Tim the option of colostomy irrigation after the formation of an end colostomy. This was an option Tim was thrilled with as unfortunately due to change in weight and abdomen shape he had sadly experienced leaks from his stoma appliance (despite trialling many different pouching systems, belts and accessories).

Two years later Tim has now had his colostomy re-sited and now manages to successfully irrigate his stoma which in his words has made such a difference to his life:

> "Life is good now. I started irrigating my colostomy which has greatly improved my quality of life. I do a demanding job, which can involve very stressful situations miles away from the nearest loo, and manage bladder and bowel well."

On the lighter side Tim says:

> "I can't remember what it's like to be 'busting' to go the loo!
>
> "I get rushed through airport security – 'You can't possibly queue, Sir, carrying those extra liquids.'
>
> "I never get caught short without any loo paper and I never leave the loo seat up!
>
> "I would not be where I am if not for the amazing specialist help from Wexham Park Hospital and also, of course, my most amazing, special wife, Carol."

The way in which Tim manages his colostomy and urinary conditions is near perfect for him, but he would like to add that people are unique. It is important that options on how to manage individual situations be explored with your stoma care nurse or healthcare professional to ensure a good quality of life

Tim summarises his experiences in a poem (right) he wrote before he found a GP who understood his bladder problem.

Laura O'Mahoney
Clinical Nurse Specialist (Stoma Care)
Frimley Health NHS Foundation Trust,
Wexham Park Hospital

BUT I CAN'T TALK TO ANYONE

I wake up again, third day this week, wet and sore.
My poor wife sleeps on, blissfully unaware.
I sit on the edge of the bed ashamed and want to cry.
Tomorrow night, I will stay up and not sleep.
But I can't talk to anyone.

All I drink now is strong black coffee, to keep me awake
Whilst at work on patrol, I look for toilets and more coffee.
It's on my mind all the time, every moment of every day.
I think I am paranoid, surely this can't go on.
But I can't talk to anyone.

I knew it would happen soon, why now in front of all
Embarrassed, ashamed, humiliated, degraded I have to go on.
A friend at work buys me some adult "pull-ups",
I stayed in the toilet ashamed; I feel despair as I put them on.
But I still can't talk to anyone.

My wife tells me to see my doctor,
This will be the third time I have tried,
Each time, I have cancelled, too embarrassed to talk.
With myself, I now despise
Because I still can't talk to anyone.

Finally with a female Doctor, I was able to talk
All the checks done, an urologist appointment was made
It would be 8 to 12 weeks as I was not going to die
Mentally, I already had done
Because I still can't talk to anyone.

With a possible 12 week wait, I still awake wet every night.
I am afraid to go out now, and want to shed tears all the time.
I hear others talk openly without shame about diabetes, dementia and all.
But it's ok; I am not going to die…I already have done.
But I can't talk to anyone.

Tim Harvey

---

†**Answer:** Tim Harvey's oil painting of Amanda Gunning, Clinical Nurse Specialist, Stoma care and **Colostomy Association** Trustee

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it's time to CHANGE

"I saw the information about the new Trio silicone range and sent off for samples. Having tried both the Siltac and the Silvex, I was pleasantly surprised by both versions. Initially, it was tricky to get them out of the packaging but once watched the video on the website it was fine but past that point they are easier to fit, have instant-grab onto the skin, and form a secure seal. They also peel off cleanly with the pouching system, leaving no residue on the skin that could compromise the seal of the next appliance.

Perhaps the most compelling benefit for me was that for the first time since having my stoma there was no discomfort under the stoma from the appliance. Before, I had a pinching sensation at the lower edge despite it properly sited which I can only attribute to pressure from the convex hydrocolloid wafer, but with the Siltac seal cushioning it, it did not feel like I was wearing a pouching system. I work in patient care in community pharmacy and will definitely be mentioning this range to the stoma patients that I see who are having problems with leaks and skin excoriation. A truly innovative product which not only improves patient experience and confidence, but also extends wear time of the appliance - offsetting the cost to prescribers through reduced frequency of appliance prescribing if this accessory product is used."

Linda, Middlesex (ileostomate)

Call us on 0800 531 6280 to order products or make an appointment with your Trio representative.

feel the difference, experience the benefit
of our advanced silicone technology

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10th Anniversary update

This month sees the highlight of our 10th anniversary: our two-day weekend of celebrations at the Royal Berkshire Conference Centre in Reading on 11–12 July.

The weekend of celebrations will feature: an open day with dozens of companies and manufacturers as well as one–to–one sessions with stoma care nurses; a fundraising gala dinner with fantastic food and cabaret style entertainment from the *House of Beau*; and a fashion show where colostomates of all ages will be parading down the catwalk, challenging perceptions of what it means to live with a stoma.

The weekend will be showcasing the proudest moments and achievements of the **Colostomy Association** of the past 10 years. In 2005, the British Colostomy Association ceased after funding was withdrawn by Macmillan. However, a group of passionate trustees and volunteers gave up their own time and money to ensure a professional, caring and compassionate service for ostomates would still be available free of charge.

In the past decade we have seen the **Colostomy Association** grow from a couple of members of staff to a full-sized team of six. Our services have grown with our 24–hour helpline staffed by a specially selected team of trained volunteers, while over 100 others can be paired to a caller depending on topic of concern, gender, cause of operation and location. *Tidings* has gone from strength to strength and is now sent out to over 20,000 people. We have a large range of free literature available on request and a private Facebook group for online ostomates.

With our new parent helpline, JOSH, and Stoma Aid around the corner – the **Colostomy Association** continues to grow, meaning we can support more people with a stoma and do more to fight the poo taboo.

The weekend's celebrations will show why that tenacious team of volunteers and trustees thought a colostomate charity was worth saving. The celebrations will show how far we've come and where we will be going next.

Of course, the weekend is also a fantastic opportunity to raise the profile of the **Colostomy Association** even more. Members of the press have been invited to come along to cover the event and to find out more about the services the **Colostomy Association** offers. Video footage will also be taken for marketing purposes. We will be providing full coverage of the weekend in the Autumn edition of *Tidings* – so even if you could not make the event, you'll still be able to see some of what happened.

At the Fundraising Gala Dinner we will also be announcing the winners of our raffle prize draw and reveal who will be winning a brand–new car. You still have until 8 July to enter our raffle. So get your ticket stubs off soon to be in with a chance of winning a Vauxhall Corsa Sting. ■

Rockabellas, House of Beau

Raffle tickets

The response to our car raffle in the last issue of *Tidings* has been incredible with over 15,000 raffle tickets sent in from **Colostomy Association** supporters, volunteers and members of the public. However, there is still the chance to take part and win yourself a Vauxhall Corsa Sting as well as other prizes.

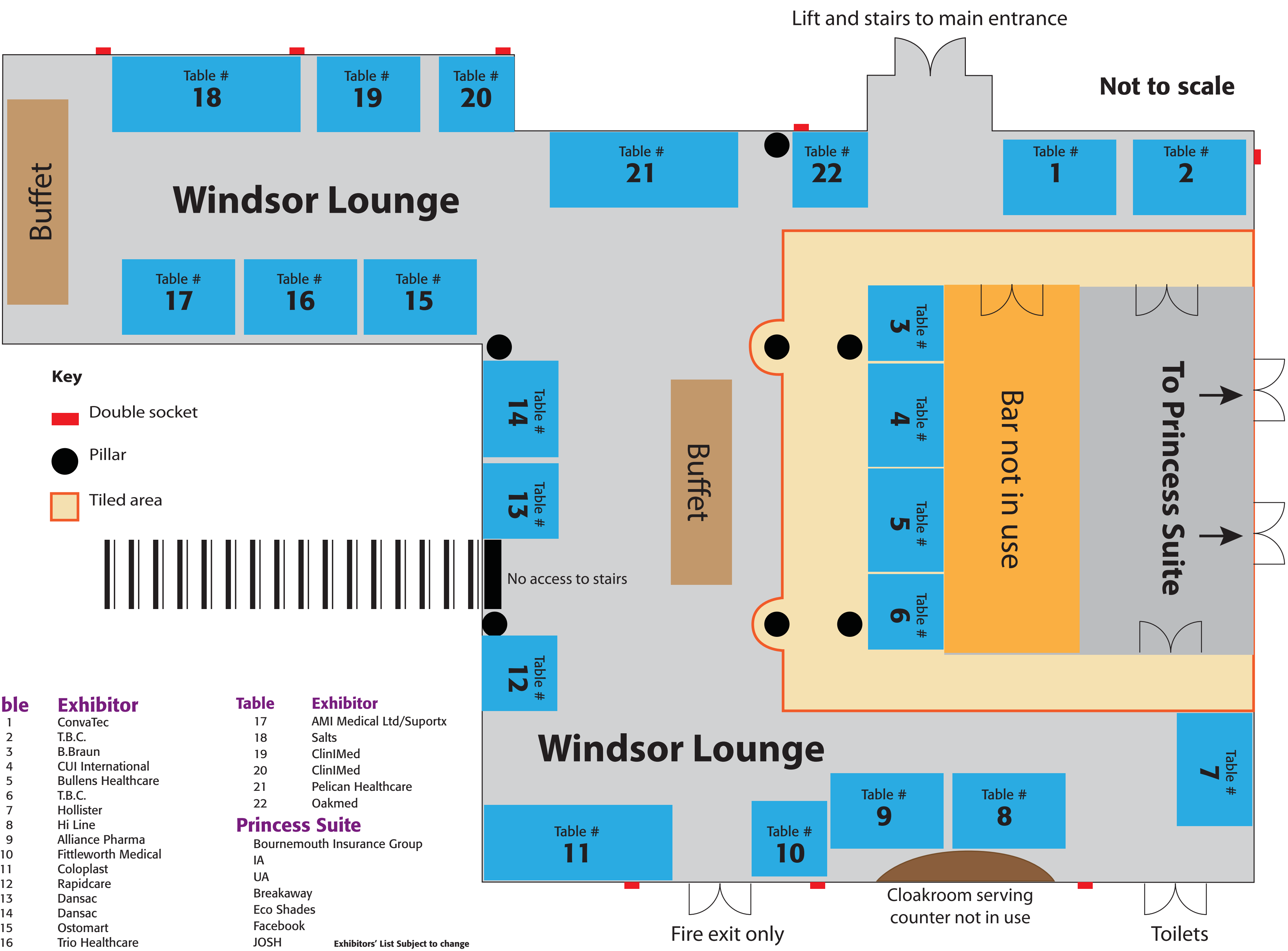
Each ticket only costs **£1** and goes towards ensuring all of the **Colostomy Association's** services remain completely free of charge. Didn't receive any tickets or want some more? Get in touch with the **Colostomy Association** and we can send you some, call: **0118 939 1537.** ■

CA Facebook group hits 3,000 members

The CA Facebook has now reached over 3,000 members meaning more people with a stoma are getting support online than ever before.

Set up in 2011, The **Colostomy Association's** private (closed) Facebook group has proven to be a vital resource for many individuals looking for quick and confidential advice. People who are looking for information or simply wishing to get something off their chest are able to share their experiences safely thanks to the CA Facebook group.

One of the admins of the Facebook group, Sarah Squire said: "Offering a closed group has made it a safe haven to discuss things you may not want your other Facebook friends to see. Facebook is now a part of many people's everyday lives so they are online already, and to have a support group readily available makes it easy for people to combine it with the social media they use already." ■



Key

🟥 Double socket

● Pillar

▨ Tiled area

Table	Exhibitor
1	ConvaTec
2	T.B.C.
3	B.Braun
4	CUI International
5	Bullens Healthcare
6	T.B.C.
7	Hollister
8	Hi Line
9	Alliance Pharma
10	Fittleworth Medical
11	Coloplast
12	Rapidcare
13	Dansac
14	Dansac
15	Ostomart
16	Trio Healthcare

Table	Exhibitor
17	AMI Medical Ltd/Suportx
18	Salts
19	ClinIMed
20	ClinIMed
21	Pelican Healthcare
22	Oakmed

Princess Suite

Bournemouth Insurance Group
IA
UA
Breakaway
Eco Shades
Facebook
JOSH

Exhibitors' List Subject to change

10th Anniversary update

There has been a great deal of interest in our special celebratory weekend and we very much appreciate everybody's involvement and support. Everyone who has submitted a booking form has definitely got a place at the event/s of their choice as we can accommodate more than 240 people!

Please remember, there is no charge to attend our open day and fashion show so if you are interested, there may well still be a few last minute places available!

Take a look at the room plan opposite to see which companies are being represented at the open day and fashion show and this will help you plan your visit.

Our open day will run from 9:30am through to 4:00pm on the Saturday. Talks kick off at 11:00am and there are chances to browse the exhibitor stands throughout the day. The venue opens for our gala dinner event at 6:30pm with food served from 7:00pm.

There will be entertainment, awards, an auction and more which run until 9:30pm where you will have the chance to dance the night away until 12:3am.

Our fashion show event will run from 10:00am until 1:00pm on the Sunday. Our models start parading down the catwalk from 11:00am and there is another chance to browse exhibitor stands if you missed the opportunity on Saturday.

Don't forget to bring along any unwanted as-new handbags for our 'Shwap' stall. Lots of as-new bags and vintage handbags have already been received ready for sale at the fashion show so you could pick up a real bargain for only £10.

Meanwhile, tickets for the fundraising gala dinner have now been sent out to everyone who has paid and it promises to be a wonderful evening.

This jacket and tie event will include a special awards ceremony, where our *Volunteer Lifetime Achievement Award* and our *Purple Iris Stoma Care Department* award will be presented, as well as the cabaret style entertainment mentioned earlier – and dancing till late.

Sponsorship has been gratefully received for various aspects of our special weekend and these include (in order of generosity): ConvaTec; Dansac; Salts Healthcare; Trio Healthcare; CliniMed; and OstoMART.

Additionally, CliniMed have kindly offered to fund a special social gathering for our highly valued volunteers this autumn. It will be a wonderful opportunity for us to thank our dedicated team for all their efforts over the past decade (or longer in many instances).

All this financial support is vital and very much appreciated. Thank you everyone and see you soon!

Exhibitors' List opposite Subject to change. ■

Some visitors and exhibitors at the 2013 Open Day

Photo Competition and 2016 Calendar

It's the time of the year that everyone looks forward to most; the sun is shining, the days are long and many of us will be travelling around the globe on holiday.

Why not share some of your best snaps with the **Colostomy Association** and our supporters to be in with a chance to feature on our 2016 calendar?

Despite improved public awareness, there is still a perception that having a stoma limits people from being able to go on holiday or travel the world. Our first time ever 2016 calendar aims to smash that perception by featuring photos from ostomates visiting all the corners of the globe.

For the competition we are looking for photos of landscapes and scenes from your holidays; whether it's the Great Wall of China or the hills of the Algarve. We want your boldest and best pictures that capture why having a stoma is no barrier to living a full life.

RULES

Only digital photographs will be accepted.

All entries must be of the highest resolution possible to be accepted to ensure the very best of quality for their reproduction into a large calendar format.

Ideally, photographs of 300 dpi (dots per inch) will be suitable – please check the *Image Properties* for your photos on your camera to see if they meet this specification before taking your photograph.

On the camera your would want to set the *Image Quality* to the ◢L with (the smooth curve, not stepped); typically these are 18Mb files that are 5184 pixels x 3456 pixels – this information will be displayed when you look at the *File Properties* on your computer.

All photos must also be of landscape orientation and scenic to fit in with the theme of our proposed calendar.

There is a special prize for 1st place where the winner will not only receive a certificate but a wall canvas of their winning photograph measuring 76cm x 50cm (30" x 20") being donated by Jessops and a free 2016 calendar. The winning photo will feature prominently on the front cover of the calendar and for one of the months inside. There are also prizes for 2nd and 3rd place with a free certificate and calendar featuring their photo.

The deadline for entries is 7th August 2015 so get snapping – if you're not going on holiday this year you can still enter – we'll accept photos from any of your previous holidays. Plus, keep an eye out for our proposed 2016 calendar which will be available to order from the **Colostomy Association** in October – keep a space free on your mantelpiece or consider buying them as Christmas presents. Details on how to order a 2016 calendar will follow in the Autumn edition of *Tidings.* Good luck with your entries everyone! ■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No-Sting Adhesive Remover with fresh mint fragrance/Dissolvant d'adhésif non irritant en vaporisateur, au parfum de menthe fraîche
SALTS HEALTHCARE

A Week in the Office

It's 9am on a Monday morning and the Colostomy Association telephones are already ringing.

L–R: Niall Norbury; Sue Hale; Jo Hammond; Arvind Anand; Giovanni Cinque; and Jo McKenzie

Logging into their computers, our two Administrators, Jo McKenzie and Jo Hammond, are faced with the large influx of online registrations via our website and lots of general CASS emails which arrive over the weekend – sometimes as many as 70 are waiting for them.

Over the course of an average week Jo and Jo could have dealt with 40+ new registrations/welcome packs and 35+ email enquiries, as many as 100+ phone calls during office hours and follow on actions from around 30 'out of hours' helpline calls handled by our wonderful team of helpline volunteers! Interestingly, some of these calls can last 40 minutes or more, depending on how much 1:1 support is needed.

It doesn't stop there though, as our records have to be updated, callers referred on to a matched volunteer, personalised packs sent out to each new supporter and arrangements made for pre-op patients so they are included in our follow up support system to help them through each stage of their journey. The most popular email and telephone call topics generally include sore skin, surplus supplies, hernia, rectal discharge, reversal and travel advice.

Our Senior Administrator, Jo McKenzie (who has been with the **Colostomy Association** for over 11 years, including as a volunteer with the then British Colostomy Association) is always busy – typically liaising with our team of over 100 UK wide volunteers about open day attendances, producing the helpline rota, organising training workshops for volunteers, processing DBS checks for the new JOSH volunteers, despatching parcels of literature to nurses and organising mailshots through stoma manufacturing representatives. Last year our volunteers attended over 330 open days around the country thanks to Jo. This is simply staggering and clearly demonstrates their incredible dedication and commitment.

Meanwhile, Jo Hammond (who has been employed with the **Colostomy Association** for almost three years) deals with the incoming/outgoing post, tracks donations, administers our 500 Club, orders ID cards, sends out RADAR keys, analyses statistics, updates the content on the **Colostomy Association** website, keeps our range of literature stocked, makes database amendments and processes our 10th anniversary attendance bookings. In an average week Jo will deal with around 160 incoming donations by cheque or telephone and send out 25 ID cards and 30 keys. This certainly keeps her out of mischief!

Additionally, both Jo and Jo are organising the fashion show taking place on Sunday 12th July so they are busy liaising with the models, overseeing the handbag "shwap" fundraising activity and discussing the arrangements with the fashion consultant, Yvonne Frost of Image-On. Quite simply, without Jo and Jo the **Colostomy Association** office would grind to a halt!

Meanwhile, other staff members (Arvind Anand our Products & Services Officer, Niall Norbury our Marketing Communications Officer and Giovanni Cinque our Fundraising Officer) are busy with a wide range of tasks. These include dealing with Tidings advertisers, producing copy for Tidings, in–house design of Tidings, updating leaflets, raising awareness through local and national media, producing a monthly e-newsletter, applying for grants for potential projects, liaising with fundraisers and creating a new fundraising pack.

As you can see, supporting over 19,000 ostomates means we are incredibly busy each week. Fortunately each week several admin volunteers help out in the office with tasks like putting together our welcome packs, answering the phone, conducting internet searches, cutting out used stamps, sticking address labels onto manufacturers' mailings and folding the raffle ticket stubs. Many of these highly valued volunteers have been involved in the office for over five years and they make a very real difference to our workloads. Luckily these lovely ladies and gents enjoy the camaraderie and the variety of tasks undertaken, knowing they are making a real difference to fellow ostomates.

Overseeing it all is our General Manager, Sue Hale, who has been with the **Colostomy Association** for three and a half years and Sue makes sure everything runs smoothly. Sue deals with the high level aspects of the Charity such as working closely with the Board of Trustees, looking after the financial matters, ensuring legal compliance, overseeing the 10th anniversary celebratory events and creating a monthly volunteer newsletter to keep everyone regularly informed. Typically, Sue will be involved in meetings with key people such as representatives from the stoma industry and other stakeholders. Sue also holds monthly supervision sessions with each staff member to ensure they are coping with their workloads and to discuss ongoing priorities.

The week doesn't end there as more often than not, Jo McKenzie or Sue Hale will take the helpline at home over the weekend if a volunteer is not able to. As you know, these calls can be received right through the night!

From Monday morning to Friday afternoon, our team are constantly working hard to support ostomates and health professionals across the UK, answering calls, funding projects, producing products, raising awareness and ensuring anyone who needs our help can access a service which is free, informative and supportive.

All in all, a very productive and hardworking team! ■

Help Colostomy Association raise funds

For your FREE donation box simply contact the office

Telephone:
0118 939 1537

or email:
cass@colostomyassociation.org.uk

to order yours today

Your Travel Checklist

On top of all the normal precautions, like making sure your travel documents are in order, take copies of important documents with you in case the originals get lost or stolen.

The ostomate needs to remember to:

- ☐ take sufficient supplies for your stay;
- ☐ take all supplies and travel stoma kit as hand luggage;
- ☐ ask the airline in advance if you need extra hand baggage for your supplies;
- ☐ 'check in' online 24 hours before departure to secure your preferred seat;
- ☐ avoid food and drink the day before you are to travel that are likely to cause upset or excessive wind;
- ☐ take medication to firm up or loosen output;
- ☐ carry your Travel Certificate with you especially when passing through immigration or security areas;
- ☐ take some form of electrolyte replacement solution in case you become dehydrated;
- ☐ drink bottled water in foreign countries, avoid ice in drinks and use bottled or boiled water to clean around your stoma area; and
- ☐ store your supplies in a cool place, out of direct sunlight.

CA Booklets, Leaflets and Factsheets are available

Simply contact:

General Enquiries:
0118 939 1537

Monday to Thursday
9am – 5pm and
Friday 9am – 3pm

or

E-mail:
cass@colostomyassociation.org.uk

or download from our

Website:
www. colostomyassociation.org.uk

Win **BIG** with our 500 club prize draw

The 500 club is a way of raising vital funds for the Colostomy Association and also gives you the chance to win cash prizes ranging from £25 to £1,000.

For only £24 per year, you will be entered into a quarterly draw for cash prizes of up to £500, £250, 3 x £100, 3 x £50 and 3 x £25.

At the end of each year a further prize of £1,000 is awarded.

Draws will take place at the end of March, June, September and December and winners will be notified shortly thereafter.

Membership is restricted to the first 500 applicants so don't delay.

500 Club March 2015 Draw Winners!

Mrs Marchant	£	353.00
Anonymous	£	176.50
Mr Sutcliffe	£	70.60
Mrs Neal	£	70.60
Anonymous	£	70.60
Mr Maddocks	£	35.30
Mr Lee	£	35.30
Anonymous	£	35.30
Mrs Jones	£	17.65
Anonymous	£	17.65
Anonymous	£	17.65

NOTE:

We would also like to apologise for an omission in our Spring edition: Mrs I Gibbs; the £1,000 winner very generously donated back to the Colostomy Association £250.00 from her winnings – thank you. The following people also kindly donated all or part of their winnings back to the Colostomy Association: Mr Maddocks donated £10; Mr Sutcliffe donated £20.60; Anonymous donated £176.50.

For more information contact us on **0118 939 1537** or download the form: **www.colostomyassociation.org.uk**

Get your chance to win with the 500 Club

Simply complete and cut out this standing order mandate, as soon as possible and return it to:

Colostomy Association,
Enterprise House
95 London Street
Reading
RG1 4QA

Note: If, at the time of any draw, the club is not fully subscribed, the **Colostomy Association** reserves the right to distribute prizes in the proportion of the subscriptions received.

Colostomy Association:
Lottery Licence no. LOT000141

500 Club entry form

My Details:

Title: Name: Surname:

Address:

Postcode:

Telephone number: Email:

Instruction to your Bank/Building Society to pay by Banker's Standing Order.

To the Manager: (Bank or Building Society)

Bank Address: Postcode:

Name(s) of Account holder(s):

Account number: Sort code:

Please pay: **NatWest Bank Market Place Reading Branch 13 Market Place RG1 2EP**

Account name: **500 Club** Account No: **89252314** Sort code: **60-17-21**

the sum of **£24.00** amount in words: **Twenty four pounds only** per year

Quoting reference: **500 Club**

Date of first payment: **(at least one month from submission)**
and thereafter on the same day every year until further notice.

Name: (IN CAPITALS)

Signature: **Date: / /2015**

Please cut along the dotted line and return to the address on this form - thank you

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New Dansac NovaLife Soft Convex – the gentle and flexible solution

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My current appliance is ___________________________

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Simply fill in the reply coupon, pop it in an envelope marked: **FREEPOST DANSAC. No stamp or further address details are required.**

Name: ____

Adress: ____

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__________________________ **Postcode:**____________

Tel: ____

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Junior Ostomy Support Helpline (JOSH)

JOSH has been giving and receiving good news this Spring, with some amazing outreach work for parents of young children and a very kind donation.

Children with stomas can often be victims of bullying and isolation. Much of this is a result of lack of education about what a stoma is, allowing negative perceptions and myths to arise. Through the **Colostomy Association** our new JOSH service has been helping children and their families understand what a stoma is with an art and craft activity – a *Pouch Craft* competition.

Throughout May, team members have been visiting nurseries and craft clubs with a sack full of unusable stoma bags. Children were then encouraged to grab a bag each and decorate them in any way they wanted with some fascinating results: drawings of gardens; rabbits; as well as self-portraits.

The idea behind *Pouch Craft* was to introduce children to a stoma bag; holding it, playing with it and realising a stoma bag is not a scary or nasty thing. The response has been overwhelming with local kids producing amazing pieces of art with just a few stickers, crayons and some glue.

As well as spreading positivity, JOSH received some good news of its own after a company kindly donated a whopping **£10,720** to the service.

Employees of the company (which wishes to remain anonymous) were able to nominate a worthy cause to receive funding; a panel of employees then evaluated the proposals and chose one they thought was most worthy. Fortunately, JOSH was chosen and has received **£10,720** as a result. The money donated will be spent on training volunteers to man the helpline, producing JOSH leaflets, sending out much needed literature packs and ensuring anyone who calls the JOSH helpline receives the best possible support and assurance.

Sasha Kelly, a JOSH volunteer who put forward the helpline for the grant said: "I wanted to nominate JOSH for funding so that we could grow the helpline, get more volunteers trained up to take calls and reach more parents who are facing the challenges I faced in those dark early days. I was ecstatic to hear that my employer awarded the full **£10,720** that I had requested for JOSH – this will cover the costs of further volunteer training and marketing for the JOSH service."

To reach a JOSH volunteer, please call the 24-hour **Colostomy Association** helpline – **0800 328 4257** – and ask for a JOSH helpliner to give you a call back. You will then be matched with an individual JOSH volunteer who will be able to talk to you about your child's bladder or bowel problems and then help you deal with any specific concerns. ■

Broaden Your Horizons This Summer...

Special features of this range of pouches include, skin friendly traditional hydrocolloid skin barrier, soft non-woven backing for optimum comfort, internal 'raincoat' layer to protect the filter, and in some, the quick drying split film front cover allows observation of the stoma and easy application. Available in a wide range of cut-to-fit and pre-cut sizes. A pouch for all occasions. Great for leisure activities.

Flat Top

" I went swimming with this pouch. I was amazed how quick the pouch dried. "

M.H - Leeds

Anatomical

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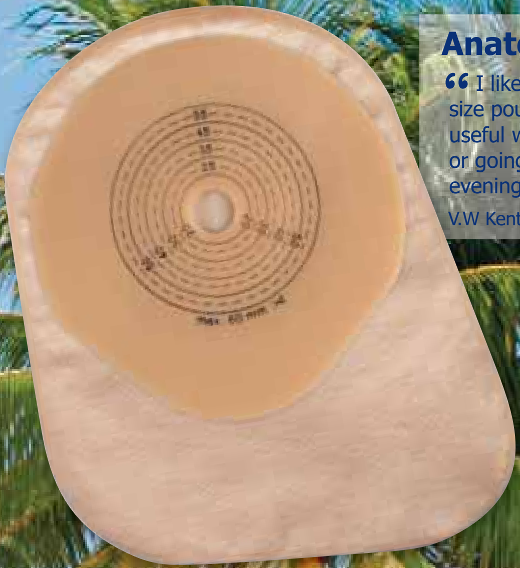
V.W Kent



Soft Convex*

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H.W - Newcastle-Upon-Tyne

Stoma Cap

" I like the size, the feel of this pouch. The material is soft and quiet. I can forget I am wearing a pouch as it is small enough not to get in the way. "

J.L - Glamorgan

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*Convex products should be used upon the advice and guidance of a Stoma Care Nurse.

Facebook Group

Meet – Cardiff


Photo: Ian Jackson

The CA Facebook group is going from strength to strength and in March this year a meet up was arranged in Cardiff, hosted by Pelican Healthcare. Sarah Squire, Trustee and Facebook group admin writes:

As soon as we start to plan the next group meet up, the Facebook admin team begin to get excited. The meets are such fun and a brilliant opportunity to catch up with friends new and old. This time we were off to Cardiff thanks to Nicola Ingledew and her team at Pelican Healthcare, and the 25 places for the meet were filled in an all–time record of just one day after the date was announced! So March 21st was in everyone's diary. My only hiccough was the small matter of a fairly big surgery four weeks before the meet when I had my rectum removed and a hernia repair. My ever worrying Dad told me there was no way I was to go but with the help of my Facebook buddies and offers to drive, lift luggage and even help with putting my socks on I was on my way, with a promise to Dad that I would rest more than play (maybe).

Group admins, Ian, Michael and Steve joined us but Sally and Natty couldn't make it this time. Sally had the rather exciting excuse of a new grandson arriving the day before the meet and Natty is getting over a spell of poor health. But they were both with us in spirit.

As has become tradition some members met up the night before at the hotel to start the party early and were already charming the hotel staff ready for the main event the next day. The full group met at lunchtime on Saturday and it was again time for hugs, or should I say *cwtches,* as we were in Wales after all! We all piled into taxis provided by Pelican and set off for a factory tour and presentations on various aspects of the company.

The staff at Pelican were fantastic – I'm not sure they have seen such an enthusiastic and lively group. Some people were able to get hands on experience and even make some stoma bags. Think we may have had a couple of members who are even thinking of a career change now as they were so good at it!

After the tour (don't tell my dad I walked round the factory!!!) we were served refreshments and heard about a couple of new ideas coming from the Pelican range. All very exciting, and they even asked us how we thought products could be improved. It was a lovely afternoon and we would like to thank all the staff involved for an informative and fun visit.

By now there were whispers of rugby scores passing round the group and Steve Clark was tapping his watch as England were about to play, so we headed back to the hotel and while some caught up with the rugby, others had a quick rest and change ready for dinner. We were joined for dinner by Nicola and Garry from Pelican who kindly provided the meal and drinks. Group admin Ian had also brought a special little friend along to the meet – Tomas Bear is the new group mascot and he proudly wears a group T–shirt. We decided to raffle Tomas in the evening along with prizes donated by all the admins, to raise some money for the **Colostomy Association.** Plus, member Denize O'Learly has taught her assistance dog Xeni a brilliant trick of picking up pound coins and dropping them into a collection bucket. Xeni is the perfect fundraiser as he is so cute people find him more and more coins. Some members also donated the deposit they had paid to secure their place at the meet and in all we raised an amazing **£362** for the **Colostomy Association** during the evening. Thank you everyone. I must admit I was exhausted by the time dinner had finished so I did the sensible thing and went to bed but the rest stayed on to talk and laugh some more. It was in all a brilliant day and again a hugely successful meet.

These meets are the perfect opportunity to meet other members, and partners can also benefit from talking to others in a similar position. By companies helping us out we are able to learn about the manufacture of the products so important to our every day life, we can feed back ideas to them and we also have a lot of laughs along the way.

Many thanks again to Pelican Healthcare for such a great event. We are already thinking about the next meet but in the mean time hope to meet up with many of our group members at the **Colostomy Association** anniversary event in Reading in July.

If you would like to join the closed CA Facebook group, search "Colostomy Association" in your facebook search box, choose the group and when you get to the group page, click on the join tab and one of the admins will add you as soon as they can. We look forward to seeing you there. ■

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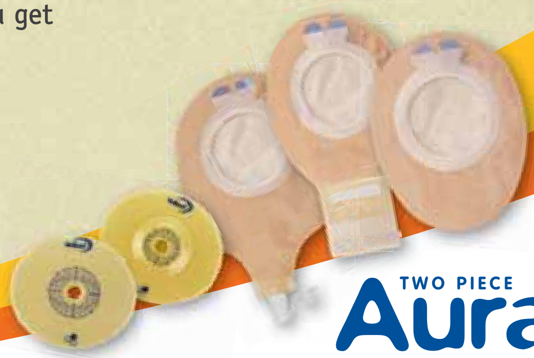

TWO PIECE Aura®2

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Canoeing was the best bit of the weekend

We've just come back from the YHA National Forest where we held our first family weekend of 2015. We welcomed twenty families, eleven of whom were new to Breakaway, and there were over seventy of us in total, I don't think we were quite as tidy as the school group they'd just had in!

The weekend was just fantastic, all the children got along together, it was as if they'd known each other for years. The boys, and a few dads, spent every spare minute outside playing football, while the rest of the parents took the time to relax and chat to the other parents about their shared experiences. On the Saturday the climbing wall came to the hostel and there were lots of smiles as the children realised that yes they could climb to the top, even though they were scared at first. There were also some fun team games to have a go at, and then in the afternoon we launched the rockets that had been built on Friday night. Some did better than others it has to be said, but there was one that really did 'go up like a rocket!'

Saturday afternoon everyone went to the local leisure centre, where we'd hired the pool. Swimming is often a real first, not just for the children, but also for adults with a stoma, and it's lovely to see their faces when they get into the pool for the first time since surgery and realise that swimming with a stoma is no different than without, your bag won't fall off and no one can see it under your swimming costume. Saturday evening saw a visit from Critterish Allsorts. This year he had brought along a chinchilla, a gigantic boa constrictor, Stoosh the skunk, a hedgehog, a lizard, some millipedes and a weird fish like creature. The kids absolutely loved it, it's a sure fire way to get them to sit quietly for two hours! While the kids were enjoying the critters the adults had a question and answer session with our professional volunteers. This is a really important part of the weekend, and the discussion is always really lively, with parents offering their experiences in response. We are so grateful to our professional volunteers for giving up their time to volunteer at our weekends, and I know the parents really appreciate it, so a huge thanks goes to Lesley Nickell, Kevin Hayles, Jules Plumb, Jeni Senior and Rachel Wade.

Sunday saw us travel to Beaumanor and Quorn for a day of activities. The younger children (and Julie!) had great fun with hide and seek in the cellars, followed by bouldering and shelter building. The older children did the high ropes and zip wire, and of course both groups got to canoe. Canoeing was the best bit of the weekend for everyone, much hilarity ensued, and much splashing of everyone, some people ended up very wet indeed! In the evening, Pareet, one of our Breakaway kids turned volunteer had his legs waxed to raise money for Breakaway. Luckily we had a professional in our midst, Sarah Oates who some of you will know from the Facebook group, and so she was able to save Pareet from our clutches and wax him properly. The kids were enthralled by it, some wanted to go further and wax his beard off!

We returned home exhausted but exhilarated after the weekend, and there was still no rest for the wicked. We're still taking bookings for our August weekend in Buckinghamshire, and we've also booked the 2016 weekends, and this is where it gets exciting... Our May 2016 weekend will be in Scotland! Yes, that's right, Breakaway are heading across the border. It is the 27-30th May 2016 at the Belmont Outdoor Centre, Meigle, near Blairgowrie. Booking is now open, so if you're in Scotland or you just fancy the trip, email us for a booking form. The August 2016 weekend will be at the YHA National Forest and booking for that weekend will open later in the year.

Hope to see you at an event in 2016! ■

More information about Breakaway Foundation.

Donate online via:
http://www.justgiving.com/breakawayvisits

Write to us or send a donation to:

Breakaway Foundation
PO BOX 7982
Swadlincote
DE11 1FB

Telephone:
01283 240253
Email:
info@breakawayfoundation.org.uk
Web:
www.breakawayfoundation.org.uk

What Should I Eat?

Sophie Medlin, registered dietitian and lecturer in dietetics at Plymouth University answers some of the questions that are frequently asked on the **Colostomy Association** Helpline.

Q: *Are there any foods everyone with a stoma should avoid?*

A: Absolutely not. Everyone is different and different foods have different effects on different people! We all have varying levels of chemicals that break down our foods and different bacteria in our guts doing different jobs. If you think a food has caused you a particular problem such as wind, try cutting it out for a week and retesting it to see if it causes the problem again. I frequently find that it is not so much the individual food but that food in combination with other foods that causes a person to have a problem. Cutting foods out unnecessarily can lead to nutritional deficiencies so if you think you have a problem but are unsure how to manage it ask your GP or stoma nurse to refer you to a dietitian.

Q: *How would the advice you give to a colostomate differ from the advice you give to an ileostomate?*

A: Colostomates still have part of their large bowel available which primarily absorbs water and salts from the stool. If you have a colostomy, you should be able to enjoy the same diet as you did before your surgery with no problems.

Ileostomates do not have their large bowel to absorb water therefore the stool is always more liquid than it would have been previously and they may need to add more salt to their food for the first six months after surgery until their small bowl makes up for the salt absorption that the large bowel used to do. The important thing for ileostomates to remember is that you can easily become dehydrated. In hot weather, when playing sport or if you develop a tummy bug, rehydrate by sipping rehydration fluids such as Dioralyte or a sports recovery drink. Some patients who have a shorter bowel will need specialist advice on this so talk to your stoma nurse or dietitian if you have any concerns.

Q: *What should a colostomate do if there has been no output from their stoma for a couple of days?*

A: Consider what your bowel action was like before your surgery. If you were prone to constipation then, it is likely that you will be more prone to be constipated even with your colostomy. Make sure you drink plenty of fluid and take some gentle exercise, if you can, to get your bowel moving. You could also try a small amount of prune juice. If it goes on longer than three days, or you are in pain and your stomach becomes swollen contact your doctor or stoma nurse.

Q: *What advice would you give to an ostomate about eating abroad?*

A: Try to relax and enjoy the food. If you are uncertain of the effect a new food might have, try a small amount and have more the next time if you have no problems. Because ileostomates are at higher risk of dehydration if they get a tummy bug it would be sensible to avoid high risk foods. These include:

- salads, such as lettuce which may have been washed in unclean water
- uncooked fruits and vegetables, unless they have been washed in safe water and peeled by the traveller
- fresh or cooked food that has been allowed to stand at room temperature in warm environments, or that has been exposed to flies, such as in an open buffet
- unpasteurised milk, cheese, ice cream and other dairy products
- raw or undercooked shellfish or seafood
- food from street traders, unless it is has been recently prepared and is served hot on clean crockery

Q: *Can eating probiotic yoghurts regularly be beneficial for a colostomate?*

A: There is some good research to show that probiotic yogurts can be of benefit to most people as they help to promote good bacteria in the large bowel. As they are shown to be of benefit to bacteria in the large bowel and people without their large bowel (ileostomates) haven't been studied yet I can't recommend them to ileostomates.

Q: *Does an ostomate need to take vitamin supplements?*

A: No more than anyone else! If you are having to cut things out of your diet to manage your output and are not managing to eat at least five portions of fruit or vegetables per day because of symptoms, then yes, it would be worth taking a vitamin supplement. If your diet is well balanced and you are able to eat plenty of vitamin and mineral rich fruit and vegetables, then no. It is important not to fall into the trap of taking different vitamins and minerals separately despite what you might read online or be told in a health food shop. We know that some vitamins and minerals compete to be absorbed in our bodies so by taking one thing in isolation over a long period you could become deficient in something else. Unless you have a vitamin or mineral deficiency that has been proven by a doctor on a blood test, there is no benefit to taking one vitamin or mineral in isolation. We know that our bodies are very good at selecting what we need from a good quality A-Z multivitamin so this is what should be taken if you have to restrict your diet. ■

Please bear in mind that the replies to these questions contain general information and if you have been advised differently by your nurse, doctor or dietitian, then their individual advice should always be followed.

A reader's response to the answer given to a question in the Spring issue of *Tidings:*

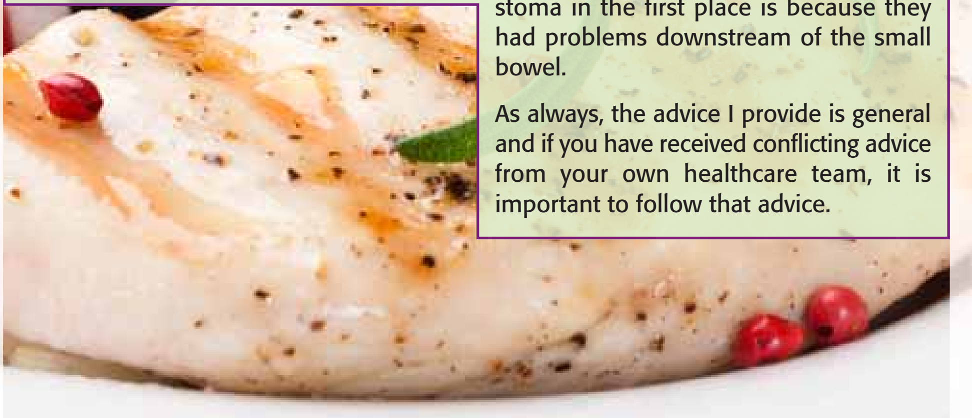
I had my colostomy eight years ago. I was surprised to read in the article by Sophie Medlin that it is alright (after an initial four to six weeks) to eat foods with skins and peels on. I was hospitalized a few years back because I had eaten an apple and left the skin on. I am very careful about chewing and the doctor said the blockage would have been caused by the apple skin. I have seen similar comments on Facebook and have a friend who was in terrible pain because of eating potato skins.

Sophie Replies:

I am sorry to hear that you had this problem, having an intestinal obstruction is extremely painful. Think of the small bowel like a hosepipe. If it is able to move freely there are no problems, if it gets wrapped around something or has a tight kink, it gets blocked. Having scarring inside the bowel or abdomen from complex or multiple surgeries makes the free movement of the small bowel much more difficult meaning that blockages are more likely. For these people, being cautious with skins and peels and pips can help to prevent blockages.

For most people with a stoma, their bowel moves freely and blockages are unlikely because the reason they had the stoma in the first place is because they had problems downstream of the small bowel.

As always, the advice I provide is general and if you have received conflicting advice from your own healthcare team, it is important to follow that advice.



Dear Nurse

Julie Rust RGN. Dip, N. MSc.
Clinical Nurse Specialist
Stoma/Colorectal
Royal Stoke University Hospital
University Hospitals of
North Midlands NHS Trust

Julie Rust became *Tidings* Nurse in December 2004. She has answered readers' letters and e-mails in every issue which has been published since then. We look forward to many more years of publishing her very sound advice.

Your medical questions about stoma care management are always welcome and important to us.

Questions received by the Editor or Colostomy Association are passed to Julie Rust RGN. Dip, N. MSc. CNS Stoma/Colorectal to review and answer. Answers are published in the next issue of *Tidings.*

Q: *I am 76 years old and have had my colon removed and now have an ileostomy. I was recommended to increase my intake of salt since the absence of the colon would reduce its absorption from the gut. However, I also have raised blood pressure which is controlled by Felodipine. Recently when my blood pressure rose somewhat I was asked if I was consuming too much salt.*

Is there any way I can decide on the appropriate amount to consume without undergoing a long medical investigation.

A: If you are eating a normal healthy diet with an assortment of different foods you should be getting a good amount of salt. If you do need to add salt to your diet make sure you do not cook with it as well as adding it to your food afterwards. The maximum you should need to add is ¼ teaspoon per 24 hour period. Obviously an increased salt intake does affect your blood pressure and therefore it is a matter of getting the balance correct, enough salt in your diet to absorb the necessary amount needed but not too much to cause an impact on your blood pressure. It may be necessary to have regular blood checks to measure the amount of salt in your body and then it can be calculated whether your normal diet is providing enough salt and therefore you do not need to add salt to your food.

Q: *I have had my stoma bag now for eight years and I am finding my waste comes in fits and starts. I can get a virtually 'quiet' week and then a few days of what I can only describe as IBS, sometimes accompanied by pain, when I have to reach for the Imodium. This has become a pattern and I have learned to live with it.*

I would be interested to know why it happens and if any other people experience this.

A: This can happen for many reasons, as it can with non ostomates. Everyone's bowel is as individual as they are as a person. Therefore, the pattern of bowel movements can differ from person to person and from week to week in an individual. It may be worth speaking to your GP if you wish for it to be investigated. It may be something as simple as what/when you are eating or it may be something such as irritable bowel syndrome (IBS) and therefore there may be treatment to help to manage the symptoms. It may be possible to regulate the bowel with the use of Fybogel, or something similar, which your GP can prescribe, or it may be beneficial to keep a food and bowel habit diary so that you can look at identifying any triggers.

Q: *Please, please, please can you help me. I had an operation two years ago which resulted in a colostomy, which is not reversible. The reason for this operation was diverticulitis with abscesses, three of which erupted leaving the sigmoid colon hardened and the bowel secreting into the bladder. I am now left with a bowel that does not stop working.*

It is not unusual for me to use 20 bags per day - on the best day not less than six to eight bags. When I am away from home, if I am unlucky, the bag will burst. As you can imagine, this leaves me with very little social life.

I am careful about what I eat and I drink only water and tea without sugar. As you will appreciate food goes in and comes out almost immediately taking with it my water content, vitamins and indeed any goodness that food should give me, resulting in my feeling that life is not worth living.

Finally I will say that I am not a massive eater, so one wonders where it all comes from.

A: I would suggest you seek a review with your stoma care nurse, your GP and possibly your consultant as this is obviously a major problem for you which is impacting significantly on your lifestyle. I cannot say why this is happening as it needs investigating to see if there is a treatment plan which helps. It may not solve the problem completely but hopefully would provide you with answers and a strategy to improve matters.

Q: *I have just been reading a question in the Dear Nurse section of the spring 2015 edition of Tidings magazine. It concerns problems with stoma output. This is very similar to my own experience. I also have a colostomy and was also prescribed Omeprazole. Having taken it for around 15 years with no side effects, I suddenly started to have problems with my stoma output. At first my output was a little loose, then over time was almost just liquid, to such an extent that I was becoming dehydrated which also had the effect of depleting my electrolytes culminating in several admissions to hospital. I refused to agree that Omeprazole was the cause of my digestive problems. However, I was persuaded to change to a different medication, Zantac in my case. Within days my output was back to normal, my electrolytes were also back to normal and I have my life back. I have no idea why my body reacted in such a sudden and radical way to a medication that I had taken for years. I wish I had known that much earlier, it would have saved several trips to hospital.*

I hope that this will be of use to others so they can avoid the problems that Omeprazole may cause.

A: Thank you for your letter, it is obviously great to hear that a simple change in medication solved your stomal output issues and this will be useful for other patients, and healthcare professionals to be aware of if they face similar problems.

Q: *I have had my colostomy for eight years, now with an accompanying hernia. I am 82 years old. When it extrudes it measures 90mm by 40mm which is the maximum width to cut the stoma bag. I have had to wear a protective belt to hold my stoma in, which gives me a great deal of pain.*

I was wondering if you could give me some advice or if any of your other readers have had a similar problem and could suggest something.

A: Parastomal hernias are a very common problem and we see many patients who manage with a hernia support belt (or garment). If you have had the belt for a while then it may be that you require a review to assess the fitting of the belt, especially if it is causing pain. The belts do deteriorate over a period of time and also your body will change size and shape. I would therefore contact your stoma care nurse or whoever arranges your abdominal support fittings to ask them to arrange a follow up appointment for a review. Hopefully this will reduce the problems you are having.

Q: *I have had a lot of bowel surgery and have been experiencing severe cramping pain when bending over or sitting in one spot bent over. I believe this is the result of adhesions and it does subside when I stand up. I believe that a blockage would be a persistent excruciating pain. I also understand that there is little that can be done to alleviate the pain of the twisting of the adhesions, but wondered if there was anything else I could do?'*

A: You do not say if this pain has been investigated and identified as being due to adhesions. If it has not I would suggest you see your GP, or your consultant if you continue under their care for follow up, so that the cause of the pain can be confirmed. If the cause has been identified as adhesions then there is really little that can be done unless your medical team feel that anti-spasmodic medications would be worth trying, or your consultant feels surgery would help. ■

What kind of stoma do you have?

When food leaves the stomach it enters the small intestine, a long coiled tube about twenty feet long. The last part of the small intestine is called the ileum. If the ileum is brought out through the abdomen to form a stoma (ostomy), this is called an **ileostomy.**

Five facts about an ileostomy

- The name comes from combining the words ileum and ostomy.
- It allows faeces to leave the body without passing through the large intestine (colon).
- It is usually on the right hand side.
- The output tends to be fairly liquid – the consistency of porridge or thick soup.
- A drainable bag is used and emptied four or five times a day.

Normally digested food passes from the small intestine directly into the large intestine or colon. If the colon is brought out through the abdomen to form a stoma (ostomy) this is called a **colostomy.**

Five facts about a colostomy

- The name comes from combining the words colon and ostomy.
- It allows faeces to leave the body without passing through the anus.
- It is usually on the left hand side.
- The output tends to be formed and firm.
- A closed bag is used and changed as necessary.

The above applies in most cases, but there can be exceptions. For example, sometimes it may be easier for a surgeon to create a colostomy on the right hand side. The output from some colostomies may be fairly liquid particularly if only a small amount of colon remains. Therefore some colostomates may prefer to use a drainable bag.

Editors Comment

Have you got a medical question or a query about stoma care management for Julie?

If so, write in and tell us:

The Editor
Colostomy Association
Enterprise House
95 London Street
Reading RG1 4QA

or e-mail your query to:
editor@colostomyassociation.org.uk

Readers' writes

Do you have a story to tell, experiences or concerns to share with other ostomates, issues to raise? Maybe you have comments and suggestions about *Tidings.* Write or e-mail us today. The editorial team looks forward to hearing from you.

Rosemary Brierley

Dear Editor

When my wife was admitted to hospital in July 2008 the last thing on our minds was that she would come out with a stoma; we thought it was an appendix problem.

However, that's what happened; she had now got a colostomy, and neither of us had any idea of what this entailed. On my first night at home, whilst she recovered in hospital from this emergency procedure, I went on the internet to see what I could find out about this new part of our lives. It was there that I found the **Colostomy Association** website.

When I rang the number shown I was put through to what, can only be described as an Angel in Waiting. I explained our new found situation and our ignorance of what lay ahead not only for my wife but also for me as a husband and helper. This oasis of calm and compassion went through all the scenario and what would be expected of me in the coming months and how I could help my wife. She was such a help that I think I will never forget that phone call. The following day when I visited my wife in hospital I was able to reassure her that life really can go on and there is help out there.

When I look back at this episode I realize that there is a part missing from *Tidings Magazine,* a page or section that is devoted to the ostomate's other half, be it a career or partner, a page where they can contribute and pass on tips about how they work together in support, how they have come to accept this change in their joint life and how in some ways it has brought them closer together.

Thank you for a very enlightening publication, I also read it from cover to cover.

Regards
B.C.M.

Dear Editor

It was quite a shock to wake up after an emergency operation to be told I had a stoma. It was due to severe diverticulitis, which had become infected and then led to my bowel rupturing.

Once home it was a bit of a steep learning curve, but I have been fortunate with my stoma, as it has behaved fairly well. Two months after I left hospital we even managed a family holiday to Disneyland Paris, which was amazing. I have managed to go back to my job as a teacher for students with severe learning difficulties with no problem at all.

When I first had my stoma I was told that it would be reversible, so in October 2013 I went back into hospital for a reversal. However, when I came round from the operation I still had my bag. The doctor explained that due to the scarring caused by my bowel rupturing he wasn't able to complete the reversal as he felt the join would rupture again. He offered to retry the reversal in a few years' time but I have refused. I don't want to take the risk of becoming poorly again, and I have learnt that life can carry on as normal with a stoma – so I am happy with my bag for life!

Helen Nobbs

Hi

I have received a letter from NHS Business Services Authority to say they are fining me a penalty charge of £40.25 plus a prescription charge of £8.05, in total £48.30, for a prescription I received after my exemption card had expired. Makes me feel like a criminal. It is bad enough having had bowel cancer and ending up with a permanent colostomy, after suffering for 30 years with Crohn's disease. I feel this is an injustice. I was not being criminal, just genuinely had not realised that my exemption card had run out after five years. I received no reminder and even my GP surgery did not know this needed updating. We get reminders for

Readers' writes

car tax etc. so why can't they send a letter, or telephone to let us know?

Please warn others about this happening. Also it says on the letter that if not paid by 16th March then it will be doubled. What a con. So angry.

Kind regards
Frances

Dear Editor

I have just received my latest edition of *Tidings,* and read with interest, and a great deal of sympathy, the letter from Denise Harper regarding her friend's problem with rectal discharge. I too am paraplegic, and had a colostomy in 2006, and I have had very similar experiences, so I will be very happy to help if I can. Please pass my email address on to them. I find the magazine a great source of help and information.

Many thanks,
E.S.T.

We contacted Denise to tell her about this offer of support. She replied that her friend would be grateful for help and advice and he was happy for us to pass on his e-mail address.

Dear Editor

I am a retired nursing sister and have had Henry, my colostomy, for 11 years. Last Christmas I lost my voice and, as a lead singer in church, I was very concerned. I went to see a vocal coach at my local speech therapy unit in our hospital. She advised me to reduce my coffee intake from four or five mugs a day to one, so I did. Apparently caffeine dries up the vocal cords.

The output from Henry became sluggish and I became unwell; no appetite, no energy and feeling very washed out. In March I had four bouts of acute abdominal pain, and nausea, lasting four hours each time.

On each occasion I had violently projectile vomiting. I saw my own GP and on the third occasion I was admitted to hospital as an emergency for investigations. As my minerals and fluids were very low I was put on an IV drip and felt a little better.

I had a CT scan and had to drink two litres of fluid before the scan. I had forgotten the side effect! It acted as a laxative and right after this scan Henry worked furiously. The scan came back clear with no obstruction, hernia or adhesions. GREAT. I went home after 72 hours admission.

Five days later it all started up again; acute abdominal pain, copious vomiting. I rang the surgery as I was too weak to go there and spoke to a doctor, I had never met before. He asked me about any changes I had made to my diet and when I told him I had reduced my coffee intake to one mug a day, he said that was where the problem started; coffee is a bowel stimulant. I was very sceptical and asked him to make an appointment for me to see my own GP the next day.

She confirmed his thoughts and told me to go back to my normal intake of coffee and put me on large doses of Lactulose. It took a few days to get going but now two weeks later I think Henry is doing well. I still have a very poor appetite but know that I must eat enough fruit and vegetables as well as a portion of protein every meal. I lost over a stone in weight during this protracted episode.

What lessons have I learnt? I will never give up coffee again! I wonder how many of your readers know about the laxative effect of coffee? I've had 11 more years of life since my diagnosis of rectal cancer. Henry literally saved my life. If it is a choice of regaining my singing voice or upsetting Henry, I know who wins, Henry every time.

Annie from Swansea

Dear Editor

I was reading one of your letters from Margaret which was very interesting. I have had a colostomy for seventeen years, plus three operations which have left me with very bad adhesion problems. However I do have fruit and plenty to drink. Also I have Lactulose which helps a lot.

I hope this will help Margaret.

Sincerely
Jean Horsley

Re: Pancaking

Thank you very much for the latest edition of *Tidings,* which I always find interesting. Could I make a request for the vexed subject of pancaking to be covered in one of your future editions? I have had a colostomy for four years now and have tried the usual ways of preventing pancaking (lubricating the pouch, covering the filter etc.) to no avail, but wonder if anyone has come up with any other ideas.

Best wishes
Ione Lee

In the next issue of Tidings *we hope to devote the From One Ostomate to Another page to pancaking so please write in and tell us what works for you.*

Dear Editor

Could I possibly prevail upon the **Colostomy Association** to mount a national campaign to encourage the providers of disabled lavatory facilities to include the very simple addition of a coat hook?

The absence of this simple device has left me fuming at motor–way services, public conveniences, railway stations, air–ports and at otherwise immaculate disabled loos provided by various organisations, companies, public bodies – in fact I have yet to discover a disabled loo with a hook for one's overcoat or jacket.

The presumption that these facilities are for the exclusive use of wheelchair–users is, I am sure, something with which many otherwise obviously fit and healthy colostomates are familiar. The glare of anger, or the sarcastic remark made by anyone in a wheelchair – or their carer – awaiting a colostomate vacating such a facility is annoying, but when changing or emptying a bag we do need a wash–basin close to a loo.

Please help. It would make such a difference and cost peanuts.

Richard Woodman

The campaign has already begun. In Issue 36 of Tidings *there is an article describing how the* ***Colostomy Association*** *has already contacted stations, rail companies and other public places about hooks, shelves and disposal bins within toilets designed for the disabled and received a positive response. We are also asking our supporters to let us know of other toilets where these are needed so we can contact the organisations responsible to request that they are installed.*

Many ostomates have also told us that they feel as you do when confronted by other people waiting to use accessible

CONTINUED ON PAGE 55, COLUMN 1

Helpful Ostomy Support Groups & Organisations

- IA The Ileostomy and Internal Pouch Support Group
  Freephone: 0800 0184 724
  www.iasupport.org

- UA Urostomy Association
  Tel: 01889 563 191
  www.urostomyassociation.org.uk

- IOA International Ostomy Association
  www.ostomyinternational.org

- Junior Ostomy Support Helpline (JOSH)
  24 Hour Helpline: 0800 328 4257
  Email:
  josh@colostomyassociation.org.uk

- Stomadata
  www.stomadata.com

- Macmillan Cancer Support
  Tel: 0808 808 00 00
  Mon - Fri: 9am - 8pm
  www.macmillan.org.uk

- Mitrofanoff Support
  Tel: 01202 937 530
  Email: info@mitrofanoffsupport.org.uk
  www.mitrofanoffsupport.co.uk

- Crohn's and Colitis UK
  Tel: 0845 130 3344
  (Mon-Fri 13:00-15:30 and 18:30-21:00)
  www.crohnsandcolitis.org.uk

- IBS Network (formerly: The Gut Trust)
  Tel: 0114 272 3253
  www.theibsnetwork.org

- Bladder and Bowel Foundation (B&BF)
  Formerly Incontact and Continence Foundation
  General enquiries: 01536 533 255
  Web:
  www.bladderandbowelfoundation.org

- Bowel Cancer UK
  Tel: 020 7940 1760
  Email: admin@bowelcanceruk.org.uk
  Web: www.bowelcanceruk.org.uk

- Beating Bowel Cancer UK
  Tel: 08450 719 301 (Lo Call rate)
  Web: www.beatingbowelcancer.org

- Gay & Lesbian Ostomates (GLO)
  formerly The United Ostomy Association
  Web: www.glo-uoaa.org

- Ostomy Lifestyle
  Tel: 0800 731 4264
  Email: admin@ostomylifestyle.org
  Web: www.ostomylifestyle.org

Stoma Care Patient Open Day event dates

For a comprehensive list of Patient Open Days events, visit the CA website.

Listings are updated throughout year.

If you are not online

contact CA on:

0118 939 1537 to find out if there is an event near you.

Note: The Colostomy Association full contact details can be found on Page 5.

Readers' writes

CONTINUED FROM PAGE 53, COLUMN 3

toilets. Therefore we have produced a Photo ID card for just this situation. It confirms your entitlement to use disabled facilities. To obtain one of these cards there is a form to complete on Page 19 of this issue of Tidings.

Dear Editor

I thought you might like to add this information into your toilet hooks campaign.

Like many others I am infuriated by the lack of hooks in toilet doors/walls so I wrote to the previous disability minister who forwarded my letter to the Government's chief architect. He reiterated that there are disabled toilet statutory features and layout (which I had been told) but he could see the need for hooks and would feed that into the next review, whenever that was. He also said I could take it up individually with each store and say it was against the equality act as it was affecting my use of a facility. I would not wish to do that for a hook. However, if the Colostomy Association and individuals wrote to the current disability minister, with a copy to the chief architect, maybe it will get altered more rapidly.

Yours faithfully

G.E F.

Dear CA

I have just received my second issue of *Tidings* and only wish I had heard of it sooner. I find it absolutely brilliant and informative.

I had my colostomy three years ago. I had rectal cancer and so had to have an abdomino perineal resection. I don't know if you have featured an article on APeR before but if not perhaps you could consider it. I am sure people would find it very interesting.

Yours

S.White (Miss)

Yes, we are looking into including an article on the different surgical procedures that can lead to a stoma in a future issue of Tidings. *As well as APeR it will also describe the Hartmann's procedure and will explain the different types of stoma.* ■

Before acting on suggestions from other ostomates you are advised to check with a doctor or stoma care nurse that this course of action is suitable for you.

Thank you for your letters and e-mails. Space permitting, we will print your contribution in the next issue of Tidings or we may hold it over for a future issue.

To contribute to the Readers' Writes page:

e-mail:
editor@colostomyassociation.org.uk

or write to:
The Editor
Colostomy Association, Enterprise House,
95 London Street, Reading RG1 4QA

Please indicate if you are willing for us to print your full name (or just your first name). In the interest of confidentiality, if you do not give us permission we will publish only your initials.

Editing may be required for reasons of clarity or space.

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If you have a product to sell, an event to advertise or a message to communicate, you can place a small advert for as little as £20. Stoma care nurses, if you would like to promote your Stoma Care Department, its services and events for FREE, then just get in touch; Contact – editor@colostomyassociation.org.uk

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CliniMed Meeting
Colossio Hotel,
33 Spittal Street, Stirling, FK8 1DX
Jul 21st 2015 – 11:00am
Tel: 08000 360 100
Email: info@clinimed.co.uk

CliniMed Meeting
Drumossie Hotel,
Old Perth Road, Inverness, IV2 5BE
Jul 22nd 2015 – 10:30am
Tel: 08000 360 100
Email: info@clinimed.co.uk

SecuriCare Meeting
Copthorne Hotel,
122 Huntly Street, Aberdeen
Jul 23rd 2015 – 10:30am – 12:30pm
Tel: 0800 585 125

CliniMed Event
Sunninghill Hotel,
Hay Street, Elgin, IV30 1NH
Jul 30th 2015 – 2:00pm
Tel: 08000 360 100
Email: info@clinimed.co.uk

CliniMed Meeting
Invercarge Hotel,
371 Perth Road, Dundee, DD2 1DG
Aug 4th 2015 – 10:30am
Tel: 08000 360 100
Email: info@clinimed.co.uk

CliniMed Meeting
Lauriestan Hotel, 15 South Crescent Road,
Ardrossan, KA22 2AS
Aug 19th 2015 – 10:30am
Tel: 08000 360 100
Email: info@clinimed.co.uk

Salts Healthcare – Edinburgh Open Day
Thistle Hotel (The King James),
107 Leith Street, Edinburgh, EH1 3SW
Aug 21st 2015 – 11:00am – 2:00pm
Contact: 0800 626 388

CliniMed Event
Fairfield House Hotel,
12 Fairfield Road, Ayr, KA7 2AS
Aug 21st 2015 – 10:30am
Tel: 08000 360 100
Email: info@clinimed.co.uk

Guernsey Ostomy Open Day
Leg Cotilg, St Peter Port, Guernsey
Sep 9th 2015 – TBC
Contact: Stoma Care
(Princess Elizabeth Hospital)
Tel: 01481 725 241

Biannual – Jersey Stoma Exhibition
Venue: TBC
Sep 9th 2015 – TBC
Contact: Stoms Care Team
Tel: 01531 445 076

Northern General Hospital/Royal Hallamshire Hospital, Sheffield Annual Stoma Exhibition/Open Day
Hillsborough Arena, Middlewood Road,
Sheffield, S6 4HA
Oct 5th 2015 – 11:00am – 3:00pm
Tel: 0114 271 4015

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For further information please Contact –
Ursula Naish, 9 Oast Meadow, Willesborough, Ashford, Kent TN24 0AS
Tel: 01233 640 863 Email: ursulanaish620@btinternet.com

colostomy association

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Note:
Please ensure that we have your correct contact details: full name, address and postal code telephone number thank you

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Address:

Postcode:

Telephone (home): Mobile:

Email:

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To the Manager: (Bank or Building Society)

Bank Address: Postcode:

Name(s) of Account holder(s):

Account number: Sort code:

I would like to make a **regular donation*** of ☐ £15 ☐ £20 ☐ £25 ☐ £50 or other amount (please state) £

☐ **monthly** ☐ **quarterly** ☐ **annually starting on the** ☐ **1st** ☐ **15th** ☐ **25th of month:** **year:**

thereafter until further notice. *Please state your donation amount in words:

(Please cancel any previous standing order in favour of this beneficiary).

Please pay: **NatWest Bank, Market Place, Reading, RG1 2EP**

Account name: **C.A. Ltd** Account No: **88781909** Sort code: **60-17-21**

Name: (IN CAPITALS)

Signature: **Date:** / / 2015

giftaid it

Thank you for your gift

Thanks to the gift aid scheme - we can reclaim money on your donation from the government. **For every pound you give us, we can claim an extra 25p.** For example, a donation of **£15 becomes £18.75 with gift aid,** at no extra cost to you.

☐ I would like the tax to be reclaimed on this donation and any eligible donations that I have made in the last four years or will make to the Colostomy Association until further notice. I confirm that I pay an amount of Income Tax and/or Capital Gains Tax at least equal to the tax, not including Council tax and VAT, that the Colostomy Association and other charities and CASCs reclaim on my donations in the appropriate year (currently 25p for every £1 donated).

Signature: **Date:** / / 2015

Optional Information: Date of Birth: Stoma Type: Colostomy ☐

Reason for your stoma: (Please tick) Ileostomy ☐

Year of operation: Urostomy ☐

(NB: The optional information is not mandatory but will help the CA learn more about you – it will not be passed on to third parties)

To donate via standing order...Please fill in the form, check your details are correct, then return this page to the Colostomy Association - thank you

colostomy association

Thank you for your support

Single donation

Your single donation/gift makes a HUGE difference to the work of the charity – CA can reach out to more colostomates their families and their carers with support, reassurance and practical advice. With your help we really can change lives - thank you.

Please fill in this form to make a Single donation. Check your details are correct, then return the completed form by post to: Colostomy Association, Enterprise House, 95 London Street, Reading, Berks RG1 4QA. Telephone: 0118 939 1537 if you have any queries.

Note: Please ensure that we have your correct contact details: full name, address, postal code and telephone number. Thank you.

My Details: Title: Name: Surname:

Address:

Postcode:

Telephone (home): Mobile:

Email:

Optional Information: Date of Birth: Stoma Type: Colostomy ☐

Reason for your stoma: (Please tick) Ileostomy ☐

Year of operation: Urostomy ☐

(NB: The optional information is not mandatory but will help the CA learn more about you – it will not be passed on to third parties)

Single donation: I wish to make a **single donation** to the **Colostomy Association** in support of the charity and its ongoing work. I have completed the **Form below** ☐ (Please tick),

Single donation/gift: a donation of £15 (or more) will help cover the cost of all our patient services

☐ (Please tick.) **Yes** I would like to make **a single donation/gift** of ☐£15 ☐£20 ☐£25 ☐£50 or

other amount (please state) £ to the **Colostomy Association**

I enclose my **cheque/postal order form** made **payable** to the **C.A. Ltd** and attach the completed Donation Form in its entirety.

Yes, I require a receipt ☐ (Please tick).

Single donations from individuals, groups and fundraising events are very welcome and greatly appreciated. So please keep them coming, no matter how small. Just £15.00 (or more) will help cover the cost of all our patient services.

Thank you for supporting CA – with your help – we can change lives!

giftaid it

Thank you for your gift

Thanks to the gift aid scheme - we can reclaim money on your donation from the government. **For every pound you give us, we can claim an extra 25p.** For example, a donation of **£15 becomes £18.75 with gift aid,** at no extra cost to you.

☐ I would like the tax to be reclaimed on this donation and any eligible donations that I have made in the last four years or will make to the Colostomy Association until further notice. I confirm that I pay an amount of Income Tax and/or Capital Gains Tax at least equal to the tax, not including Council tax and VAT, that the Colostomy Association and other charities and CASCs reclaim on my donations in the appropriate year (currently 25p for every £1 donated).

Signature: **Date:** / / 2015

To make a single donation...Please fill in the form, check your details are correct, then return this page to the Colostomy Association - thank you

Registered Office: Enterprise House, 95 London Street, Reading RG1 4QA

Registered Charity No: 1113471

Connect – Harlow and District Stoma Group

Support Groups are places where people can share personal stories, express emotions, and be heard in an atmosphere of acceptance, understanding, and encouragement. Participants share information and resources. By helping others, people in a support group strengthen and empower themselves.

Inspired by Judy Colston of Stevenage Ostomistics and her article in the winter issue of *Tidings* on sharing support group ideas, I'd like to tell you about Connect. The stoma care clinical nurse specialist at The Princess Alexandra Hospital NHS Trust, Tracey Hart, in conjunction with Jules Plumb of Dansac, was instrumental in setting up Connect which, as you would expect, has many similarities with other groups.

In May 2009 Tracey invited some of her ostomates to the Park Hotel in Harlow to discuss starting a group, and pretty soon we were holding an inaugural meeting at the social club in the grounds of the hospital, arranged by the secretary to the stoma care department, Janice King. Before we knew it, we had a newly formed committee of four volunteers, a group name, our own logo (designed by the father of one of our early members) and, with the help of the leader of the Mid Essex Stoma Support group (MESS), a constitution.

Membership fees were set and a membership form, letter of introduction and posters to be displayed in hospital wards, out–patient areas and GP surgeries etc, were printed ready to be sent out. To launch the group the local press was contacted and a 1.5m (5ft) banner was produced for our own stand at a stoma care Open Day, organised by Tracey, which was attended by representatives from most of the supply companies.

The primary aim of the group is to provide an opportunity for ostomates to meet informally and to connect with other members by sharing their experiences and offering each other emotional support and advice. Our regular monthly meetings usually include an informative and often amusing presentation by a guest speaker or healthcare professional, and occasionally a representative from an appliance manufacturer will bring along and display a selection of their newest products.

For many members, particularly those living on their own, the friendly atmosphere of the meetings provides a social lifeline and, just like Stevenage Ostomistics, this is supplemented throughout the year by organised outings and activities. Also in common with Stevenage Ostomistics we hold raffles with prizes donated by members, occasional get–togethers with a pub meal and an annual Christmas lunch which is held at the local golf club.

Since that inaugural meeting the group has gone from strength to strength and is now a vibrant and successful support group and social network. Membership is open to ostomates and their partners and numbers have grown steadily over the years to the current level of 89, consisting of 23 single and 33 joint members.

The group meetings are held on the second Tuesday of each month in the main hall at St Thomas More Roman Catholic Church in Hodings Road, Harlow, which is open to members from 10.00 am to 1.00 pm. We have use of the kitchen area but we supply our own equipment for making tea or coffee, which is provided, with biscuits, free of charge. Funding to cover the cost of hall rental, refreshments, miscellaneous purchases and speakers etc. is raised through membership subscriptions, raffles, book sales and donations from ostomates and suppliers.

Details of guest speakers and forthcoming activities are listed on a printed *Programme of Events,* which is distributed to all members, and after each meeting members are encouraged to write in our *Comments Book.*

As numbers grew we increased the size of the committee from four to six, and to help members get to know each other quicker we now provide name badges for them to wear at meetings. One member of the committee has also taken on the unofficial role of welfare officer, which involves keeping in touch with members needing practical help now and then.

To mark the occasion of our 5th anniversary in 2014, we introduced an annual newsletter and presented all members with a ballpen printed with the Connect logo. The newsletter and pen are now used to promote the group and encourage potential new members to join us.

New members are always welcome, so if you are a stoma patient living in Harlow or the surrounding district areas of West Essex and you would like to come along to one of our meetings, please feel free to contact us via our social secretary **Lin Hart** on **01279 505273**, or via **Tracey** or **Janice** in the hospital stoma care department on **01279 827072**.

Alan Marshall

If you would like to see your support group featured here, please telephone the Editor on: 0118 918 0500 or send your article and photos by post to: Editor, Colostomy Association, Enterprise House, 95 London Street, Reading RG1 4QA or if you prefer email your article and photos to: editor@colostomyassociation.org.uk

Support Groups are places where people can share personal stories, express emotions, and be heard in an atmosphere of acceptance, understanding, and encouragement. Participants share information and resources. By helping others, people in a support group strengthen and empower themselves.

Stoma support groups
in your county

England

B

Bedfordshire

Saturday Social Club
Karen Richards: 0123 479 2278

Berkshire

E.B.O.C (East Berkshire Ostomy Club)
Jackie Dudley: 0134 442 6652

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

W.B.O.C (West Berkshire Ostomy Club)
Jackie Dudley: 0134 442 6652

Bristol

Bristol Ostomy Self Support (BOSS)
Janet on 01934 248 114 or Rob on 0117 966 8021

Buckinghamshire

Milton Keynes Stoma Association
Joanne Dickson 0190 831 8262

C

Cambridgeshire

Connections Cancer & Colostomy Group
Bev or Sue Scott 0135 386 0356/ 0776 695 8811 or Barbara Hunt 0135 386 2133

Peterborough Stoma Support Group - Ostomistics
Alan Wright 0135 465 3290 / 07836 661 102

Cheshire

Countess of Chester Hospital Stoma Support Group
Danielle Kirkham 0124 436 6170

Stockport Support Group
Angela Simpson: 0161 320 9400 / 0800 652 6667

Stoma Support Group
Catherine McIntosh: Crewe 01270 666 985

Warrington Ostomy Support Group
Jane Shaw: 0192 566 2103

Cleveland

Oops Group
Julie Morrisroe/Carol Younger: 0128 728 4113

Co. Durham

Bishop Auckland Stoma Care Group
Betty: 0138 881 4535

Darlington Support Group
Sister Jacqui Atkinson: 01325 743005

Cornwall

Carnon Downs Ostomy Support Group
Ken Jones: 0187 286 3106 or www.cornwallostomysupport.org.uk

Cornwall Bowel Cancer Support Group
Peter Yorke: 01726 821 280 or email quilpusha@gmail.com or website www.cornwall-bowel-cancer-support-group

Optimists
Sue Hatton: 0132 634 0058

Ostomist and Carers Support Group
Christine Davey: 0120 883 1471

Cumbria

Grange Cancer Support Drop in
Marie: 0153 953 3279

D

Derbyshire

Diverted Local Stoma Support Group
Diane Manning: 0128 354 1311

Devon

Mid Devon Ostomy Support Group
Janice: 0136 377 6417 or jdkelly234@gmail.com

Dorset

Colostomy Urostomy Pouch Ileostomy of Dorset (CUPID)
Jenny Pipe: 0120 274 0440

Colostomy Urostomy Pouch Ileostomy of Dorset (CUPID)
Beryl Andrews 0120 248 3303

Colostomy, Urostomy, Pouch & Ileostomy of Dorset - CUPID (West Dorset)
Colin Clare - 0130 585 3238

E

East Midlands

Newhall Stoma Support Group
Diana Manning: 0128 354 1311 or Helena: 07932 331 850

Essex

Connect
Lin Hart 0127 950 5273

Mid Essex Stoma Support Group
Paul Foulger: 0124 522 4374, Jeanette Johnson: 0137 651 1862

N.E.S.S (North Essex Stoma Support)
Secretary: Brian Waller: 0120 654 0449

Optimistic Ostomates
Carol Booth: 0170 238 5510 or Angela Taylor: 0170 238 5509

STEPS
Jackie: 0126 845 1937

G

Gloucestershire

Ladies Big Op Group
Gill Hopkins: 0300 422 4363. Please Note: For ladies with one or two permanent stomas

Vale Stoma Support Group
jfn.dursley@gmail.com or text 07941 827 393

H

Hampshire

Solent Ostomates Support Group (New Forest Branch)
Carole Summer: 07527 707 069

Solent Ostomates Support Group (S.O.S.)
Carole Summer: 07527 707 069

Wessex Urology Support Group
Adrian Kuczynzki: 07910 786 978

Herefordshire

Bums on Tums - Herefordshire Ostomies Support Group
Carol Steele 0143 288 0656 / carolsteeleglo@gmail.com

Colonise
Anastasia 0172 776 0981

Hertford Stoma Support Group
Ralda: 0199 253 5311

Stevenage Ostomistics
Judy Colston: 0143 835 4018 / neilcolston@btinternet.com or Alfred: 0176 731 6958

I

Isle of Man

IOM Bowel Cancer Patient and Carer Group
P Caine: 07624 480 973

Stoma Support Group
Carole Cringle stoma nurse: 0162 465 0212

Isle of Wight

Optimistics
CNS's Andie Coates & Amanda Broadbridge 0198 353 4009

Semi-Colon Club
Tony Crowson on 0198 355 9326 or CNS Helen Fulford 0198 353 4180

K

Kent

Ashford Stoma Support Group
Ron Huckstep 07941 310 681/ Margaret Webb 0123 362 8807

Atoms Support Group
Maria Culleton, SCN: 0122 776 9679 or 07827 997 424

Dartford Ostomy Group Support (DOGS)
Tracey, John or Sue: 07948 974 350 or dogs-uk@hotmail.com

Dover Stoma Friends Group Support
Julie Bell: 07771 345 703 or Ros Marshall: 0130 482 2696 or June Golding (Organiser): 0130 482 2696

M.O.G.S (Medway Ostomy Group Support)
Helen Or Tracey: 07773 605 534

Maidstone Stoma Support Group
Judy/Kirsty: 0162 222 4305

Royal Tunbridge Bowel Cancer Support Group
Bronwen Tetley CNS: 0189 252 6111 x 2287

Thanet Stoma Buddies Support Group
Phil (Secretary) 0184 358 7769

L

Lancashire

North Manchester and Bury Stoma Support Group
Julie Meadows (SCN) 0161 720 2815 or 07841 206 910

Oldham Stoma Support
June Wilde: 0161 312 5538

Tameside Ostomisticles
Paul Seavers on 07771 359 046

Trafford Bowel Care
Jackie Carey Secretary: 0161 748 9659, Doreen: 0161 962 7818, John: 0161 748 4655

Leicestershire

Kirby Ostomy Support Group. Colostomy, Ileostomy and Urostomy in Leicestershire
Janet Cooper: 0116 239 2844 / kosg2013@btinternet.com

Lincolnshire

Friends East Coast Support Group
Betty: 0120 572 4120, Sheila: 0120 536 4493

Grantham Support Group
Bobbie/Amanda: 0147 646 4822 or grantham.colorectal@ulh.nhs

March Group
Sharon Palmer: 07414 828 867 or sharonpalmer44sp@gmail.com

Sutton Bridge and Long Sutton Ostomy Group
0140 635 1617

London

Bowel Cancer Newham
Scyana: 020 8553 5366 scyana@tiscali.co.uk

ESSence (Ealing Stoma Support Group)
Wendy Hetherington: 07717 335 884

Homerton Hospital Bowel & Stoma Support Group
Angela Davy: 020 8510 5318 or 020 8510 7599

Rectangle - Colorectal Cancer Support Group
Regina Raymond 020 7472 6299

South Woodford Support Group
Nurse Christina and Lisa: 020 8535 6563

St. Thomas' Hospital
CNS: 020 7188 5918

Surrey & South London Bowel Cancer Support Group
Sue Berry: 0173 755 3134 or John Amos: 020 8668 0796

M

Merseyside

I.C.U.P.S
SCN: 0151 604 7399

St Helens Cancer Support Group
Office: 01744 21831, Denys Floyd: 01744 884097 or email: contact@sthelenscancersupportgroup.org

Middlesex

Inside Out
Sarah Varma: 020 8235 4110 Bob (chairman): 020 8428 4242

Semi-Colon Club
Pat Black or Kathryn Foskett on 0189 527 9391

N

Norfolk

Kings Lynn Ostomy Friendship Support Group
For more info please call 0155 369 1370 / 768271 / 775698

Stars
Anne Browne: 0160 366 1751

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull: 07714 479 320

Hexham Ostomy Group
Judith on 07967 927 286

Northumberland Cancer Support
members@northumberlandcancersupportgroup.co.uk

Nottinghamshire

North Notts Stoma Support Group
Tore and Nicky Norman: 0177 371 5460

Nottingham Colostomy, Ileostomy & Urostomy support group
Rosemary Brierley: 0115 982 6691

Nottingham Stoma Support
Jenny or Kate: 0115 962 7736/ Mrs B Heath: 0115 966 3073

O

Oxfordshire

Oxfordshire Ostomy Fellowship
Pat Longworth: 0123 552 4163

Shropshire

B.O.T.S. (Bums on Tums)
Irene Constable on 0169 123 8357

Somerset

Devon IA
Martin Hornby: 01458 251 095 or email: devon@iasupport.org

Staffordshire

Outlook
Moira Hammond 07788 402 195

Suffolk

East Suffolk Ostomy Group
Marion Fisher: 0147 331 1204

James Pagett Ostomy Support Group
Sandra Hutchings: 0150 258 5955

West Suffolk & District Stoma Group
Jessica Pitt stoma nurse: 0163 851 5525

Surrey

Epsom and District Stoma Support Group
Lindsay, Trevor or Sheena: 0137 273 5925

Sussex

Brighton & District Support after Stomas (SAS)
Sylvia Bottomley: 0127 355 4407

Chichester Stoma support Group
The Stoma Care Team 0124 383 1527

The Ostomy Friends Group
Jane Quigley: 0132 341 7400 ext 4552

West Sussex Princess Royal Stoma Support
Tina Walker: 0144 444 1881 ext 8318

T

Tyne & Wear

Gateshead Stoma Patient and Carer Support Group
Stoma Care Nurses: 0191 445 3152 or email stuart.sutcliffe81@yahoo.com

Royal Victoria Infirmary Support Group
Gordon Weatherburn: 0191 234 1109

W

West Midlands

Coventry Stoma Support
Martin: 07947 385 643

Wiltshire

Swindon IA
www.swindon-ia.org.uk

Wessex Stoma Support Group
Michael Slater: wessex.stoma@yahoo.co.uk or on 0172 274 1233

Worcestershire

Kidderminster & District Collossus Support Group
Brendon Drew: 0129 940 0843

Y

Yorkshire

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

Airedale Stoma Support
Sue Hall: 0153 521 0483

Barnsley Bottoms Up Stoma Support Group
Stoma Nurses 0122 643 2528 or Celia Utley (Chairman) 0122 628 4262

Behind You (Calderdale & Huddersfield Bowel Cancer Support Group)
Stoma Care Nurses: 0148 435 5062

Dewsbury & District Ostomy
Janet Edmond: 01924 512 041 or 01924 512 072

Leeds Bowel Cancer Support Group
Lynda Castle (Colorectal Nurse Specialist) 0113 206 5535

Redbridge Ostomists Club
Stoma Nurses - Chris/Lisa: 020 8970 8321

Rotherham Ostomates Caring Support
Karen Kilford: 07880 575 758

Scarborough Stoma Support Group
Sister Jean Campbell: 0172 334 2388, Amanda Rowe: 0172 334 2446

The Hull and East Riding Colostomy Support Group
Pete Smith: 07989 565 335 or Pete Rennard: 07939 518 642 / 0148 279 3966 or Rosanna Grimsby: 0148 280 1575. www.hercosg.org.uk

Scotland

Ayrshire

Ayrshire & Arran Stoma Support Group
Jim Krasewitz: 0129 222 0945

Stoma Care And Recovery (SCAR)
Maggie: 0129 427 1060/ 0781 773 6147 maggie13@sky.com or Rhona: 0129 455 7478

Fife

Fife Ostomy Support Group
Ishbel Barr: 0159 277 2200

Lanarkshire

G66 Support Group
Les Ireland 0141 776 3866

Glasgow Stoma Support group
Chairperson: Maureen O'Donnell: 0123 643 6479

Scottish Borders

Stoma Support Group
Nancy Fraser: nancyfraser@talktalk.net or 0145 037 4012. Fiona Gentleman: r.gentleman@sky.com or 0145 037 1063

Wales

Bridgend

Bridgend Ostomy Patients Support Group
Anita Brankley (Secretary) 0165 664 5602 or Pat Jones 0165 678 6103

Denbighshire

GOSH (West Lothian)
Scott Pattison: 07502 163 644

North Wales Ostomy Support Group
Debi Devine 07876 762 503 / Hazel Duke 07976 817 246 / Email: devinetherapies@btinternet.com

The Bracken Trust Cancer Support Centre
Helen Davies: 01597 823646

Gwent

Blaenau Gwent Self Help
Celia McKelvie: 0187 385 2672 After 6pm

Cwmbran Ostomy Support Group (COSG)
Philippa Lewis: 01633 791 339 / 07504 713 069

Mid Glamorgan

C.A.S.S Colorectal and Stoma Support Group
Colorectal Nurse Team on 0168 572 8205

Pembrokeshire

PSA (Pembrokeshire Stoma Association)
Roy Whitfield 0143 776 0701

Rhondda Cynon Taf

Royal Glamorgan Stoma Care Support Group
Domenica Lear 0144 344 3053

Swansea

Swansea Ostomy Self Help Group
Glynis Jenkins: 0179 241 8245

Channel Islands

Guernsey

Guernsey Ostomates
Luci Deane 0148 123 6077 / lucideane58@gmail.com

Northern Ireland

Co. Antrim

Colostomy Association Volunteers Northern Ireland
Chris Wright: 07720 717 771

Mater Hospital
Karen Boyd - Stoma Nurse: 028 9074 1211 Ext 2329

Royal Victoria Hospital - Belfast
Sarah Haughey/Audrey Steele: 028 9024 0503 Ext 3483

Co. Armagh

Craigavon Area Hospital
Mary Jo/Bernie: 028 3861 2721

Daisy Hill Hospital Support Group
Bernie Trainor: 028 3083 5000 Ext 2222

Co. Down

North Down Stoma Support Group
Adrian Ewing on 07850 741 511

Ulster Hospital
Hazel/Martina: 028 9055 0498

Co. Fermanagh

Erne Hospital
To be confirmed

Londonderry

Causeway Support Group
Mary Kane: 028 7034 6264

Republic of Ireland

Co. Mayo

Mayo Stoma Support
Marion Martyn: 094 902 1733

Dublin

Bowel Cancer Support Group (ICS)
National Cancer Helpline: (00 353) 1 800 200 700 or Olwyn Ryan: (00 353) 1 231 0500

France

Provence

Stoma France
Adrian March:+33 (0)49 450 1136 or email info@stoma.fr

Kosovo

Kosovo

Kosovo Ostomy
Arta Uka: kosovoostomy@gmail.com

Spain

Alicante

Costa Brava
http://www.ostomyinspain.org/

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Fill in the regular donation form on page 57

CA NEWS FROM THE OFFICE

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Fittleworth is a specialist in home dispensary for ostomy, urology and wound care that promises not to change your prescription, except with the consent of the prescribing nurse or GP. We call this **Clinical Respect**.

- We do not amend, substitute or add anything to your prescription unless prior approval has been received from your prescriber/clinician
- We do not `sell' to you or suggest accessories should be added
- We support you and your care by delivering a quality prescription home delivery service ensuring all regulatory requirements are adhered to
- We work closely with the clinician complying with any instructions issued
- We recognise the prescribing authority and our professional responsibilities to both you and the clinician
- We recognise the cost pressure on the NHS and work with your clinician to ensure the NHS receives value for money and a quality dispensing service
- We comply with the NHS appliance dispensing regulations
- All Information Governance and Data Protection regulations are audited and adhered to

For further information on our service or to register,
please contact us on **0800 378 846** or visit **www.fittleworth.com**

Simply... a secure home delivery service

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Tidings-0715

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