Autumn 2016 | Issue 43

colostomy association

Tidings

Helping **ostomates** since **1967**

Cover story

- **Finding a New Challenge**

Inside

- **Surgery resulting in stoma formation**
- **The first five years after cancer**

New regular feature

- **Young adults' page**


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Cover picture
Philip Young as a volunteer Guard on the Gloucestershire Warwickshire Steam Railway.
(see Real Lives p30–31)
(*photograph taken by David Staniforth*)

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dear READERS

The editorial team always welcome feedback and suggestions from our readers. Recently we have received several comments that the stories and articles in *Tidings* tend to concentrate on cancer. We hope to address this in a future issue and include more articles about the many other reasons for stoma formation, and stories from people who have stomas as a result of a range of medical conditions.

In the meantime, however, I hope that *There's Humour in a Tumour*, written for us by a retired journalist, will make you smile and that you will enjoy reading our cover story, *Finding a New Challenge* by Philip Young who recently joined us on the editorial team.

While it is uplifting to read these positive stories, I know from the letters received for the Readers' Writes page that once cancer has been treated the fear of the disease coming back can remain. To acknowledge this we asked the charity Beating Bowel Cancer to write about *The First Five Years after Cancer*: the follow–up tests and how to cope with the stress and worry these may cause.

Not only are stomas formed for different reasons but, as you know, there are different types of stomas: some are temporary while others are permanent. Jennie Burch, Enhanced Recovery Nurse Facilitator at St Marks Hospital explains how the operations to create these stomas differ and how one may be more appropriate than another for different medical conditions. A Hartmann's procedure is generally the stoma of choice in emergency surgery for diverticulitis which is the second most common reason (after cancer) for forming a stoma. Cathy, who describes her experience of both diverticulitis and leukaemia in *Looking Forward not Backwards*, has this type of stoma.

Crohn's disease led to Molly's surgery at the age of 19. Molly first wrote for *Tidings* a year later to tell readers how she had found the **Colostomy Association** very helpful and supportive in the early days and as a result she had climbed Snowdon and raised almost **£1,000** for the Association. Then in the spring issue of *Tidings* she wrote about how she recently qualified as a nurse. She has now kindly agreed to write the first article for our new Young Adults' page. Molly tells us how her many hospital admissions have helped her understand how her patients feel, and about the added challenge a stoma brings when she works shifts on the wards.

With a wide range of stoma appliances to choose from in the UK it is possible for ostomates to lead the life they had before surgery, go back to work if they wish, but this is not the case in the developing countries. This was brought home to us by an article we received from the son of a teacher who, following an operation for bowel cancer, was unable to return to his profession because modern appliances are not available in Ethiopia. A British nurse, who volunteers at a hospital in Gondar, contacted the **Colostomy Association** and through the Stoma Aid scheme we have been able to help.

So yes, the majority of the stories this time are from people who have had cancer but in our next issue we will attempt to restore the balance. However, we cannot do this without your help, so please all you readers who have had a stoma for other reasons do write in and tell us why you needed to have a colostomy.

We look forward to hearing from you.

Rosemary Brierley
Editor

editor@colostomyassociation.org.uk

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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

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By telephone:
General Enquiries: 0118 939 1537

Stoma care queries only:
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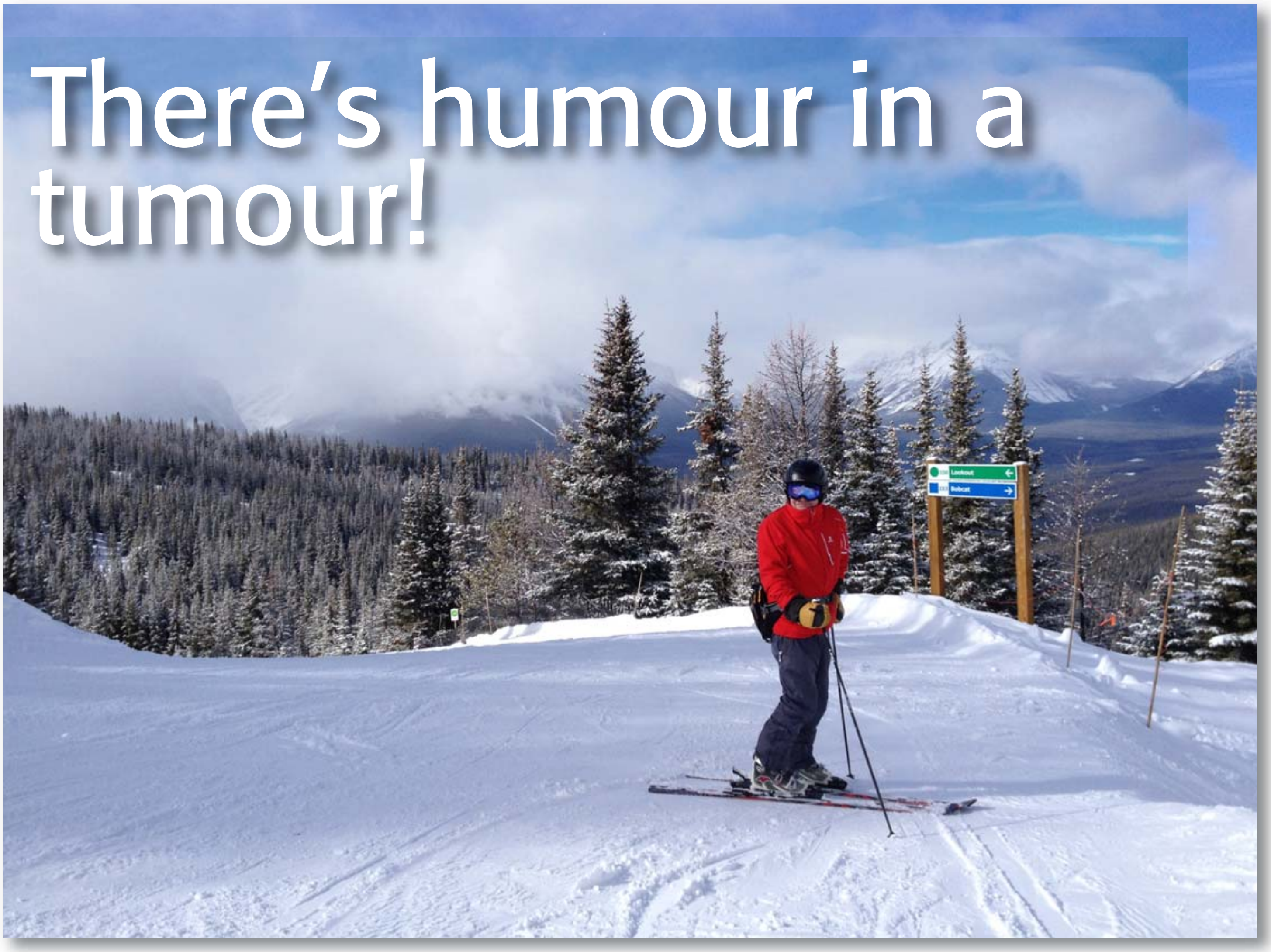
There's humour in a tumour!



SO that was it. It had taken the consultant surgeon just a few seconds to confirm what I had suspected. I had bowel cancer. Possibly because it wasn't a surprise or a medical bolt from the blue there were no tears, tantrums or any sort of traumatic reaction. Just a polite "OK, thank you."

Well, now I knew for certain. I had cancer. The Big C, the disease/condition which strikes terror into so many. Just having to name it is a struggle. There are those who when they get to the word in a sentence lower their voices as though saying cancer is an embarrassment. Others tend to be more radical. When they reach the part of the sentence where they are supposed to say the word they can't even bring themselves to utter it and so mime it. It's as though they regard it not only as embarrassing but something akin to a crude expression used to describe something nasty.

On the drive home from the Luton and Dunstable Hospital I was more concerned with why I wasn't feeling fear or anger at the news I had been given. I mean, I had cancer (shhh), faced major surgery and a permanent stoma. Perhaps I was in shock or disbelief but in truth I felt OK but concerned about how our three grown up sons and relatives would take the news.

One holiday in the sunshine in Gozo had to be cancelled but I was determined our planned ski holiday in Lake Louise in Canada, just four months after my scheduled laparascopic assisted abdomino–perineal excision of rectum, would go ahead. In retrospect I can see that the ski holiday in Canada, the seventh time we had flown over there to hit the slopes, was actually an incentive, a goal.

But first there were other things on which to concentrate: like meeting the enhanced recovery team nurses and the stoma nurses. I would have a permanent stoma and was presented with a stoma bag to wear at home to get a feel for it. The nurse also marked where the real thing would go. It was all a bit surreal but my big worry was – how will I be able to ski with that under my salopettes? I mean, I would also have to carry spare stoma bags, disposal bags and wipes with me on the slopes. And what if I had a fall and literally hit the slopes? Would the stoma bag split? It was all more of a worry than the operation.

It was one of the stoma nurses who showed me a copy of the *Tidings* magazine and it was seeing this that encouraged me to write about my experiences. If my story could help others and show that the diagnosis of cancer needn't necessarily be all doom and gloom then all well and good. Being a retired journalist meant it was no real problem putting pen to paper, or fingers to keyboard. And one thing that kept me 'sane' was my habit of looking for and usually finding something amusing in most situations. I mean, even with cancer (shhh) there can be humour in a tumour.

Take the stoma nurses, for example. Just how, I wondered, would they refer to the waste product destined for the bag? I had some strange thoughts. Perhaps they would be crossword fanatics and say something like: "Right Richard, concerning the carp, anagram, four letters, crude form of excreta…" In reality it turned out to be something very unmedical and was referred to as poo!

OK, fast forward to the operation day. Who remembers the bowel evacuation experience? Later sitting on my special cut–out cushion to ease the pressure on what my grandchildren came to refer to as grandpa's 'was bum', I can look at the bowel evacuation experience with a certain degree of nostalgia – the nurse administering the enema, the wait for peristalsis to kick in and then "Out of the way or this could get messy."

How, I hear you say, can that be something to look back on with amusement, if not affection? Well, after seven decades of going to the loo in the conventional way, minus the time I was in nappies, this was the last time it was going to happen in a sitting position. Yes, I remember it well. It was almost a "Dear Diary…" moment. Now it's all changed. Sitting, standing, resting, sleeping, walking, it doesn't matter. So long as you've remembered to put a stoma bag on that is!

Anyway, the five or six hour operation to remove a four centimetre tumour, along with 23 nymph nodes, got under way on Tuesday morning 13 October 2015. I clearly remember being shown into the anaesthetic room and meeting the consultant anaesthetist, his registrar and one of the nurses. It was relaxed and I was only slightly apprehensive as the numerous lines went in, the epidural was administered and the surgeon came in to say hello and to check everything was OK. Yet with all this going on and with the realisation that in a few minutes I would be on the operating table, shaved, catheter in, tube down my throat having my insides remodelled and rearranged, my sense of humour returned. After all, it wasn't my sense of humour they were going to remove.

Yes, it was certainly a very big day for me but for the consultant surgeon, as he went about excising my rectum, I wondered if he also regarded it as a big day or to him was this just another day at the orifice!

Anyway, the good news. We went skiing OK. I fell over several times, my bag didn't split and carrying the spares/wipes/disposal bags was no problem. A few months later I had an MRI scan and my chemotherapy was cancelled after 14 weeks as it was no longer necessary and I am back playing golf again. The bad news, my wife was stretchered off the mountain in Canada with a damaged knee, I was admitted to hospital the day after we returned with urinary sepsis and a few months later I had a mild stroke.

Still, you've got to smile!

PS. *And there's more good news. Next year's ski holiday, this time in Italy, is booked.*

Life Stories Needed

Do you have a unique story or experience you'd like to share with others?

Tidings is the most widely-read stoma publication in the UK. Your story has the potential to change the lives of other readers who may be struggling to adjust to life with a stoma.

We are always on the lookout for new stories to feature in future editions of *Tidings* magazine. Whether your story is positive, funny or sad we'd love to hear from you.

To submit a story, or if you have any questions, please get in touch via e-mail **editor@colostomyassociation.org.uk**

or in a letter to:

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

Please make sure you include your full name and address and telephone number so we can contact you. Additionally, please mention whether the Colostomy Association has permission to publish your story and whether you would like us to use your full name or just your first name.

Young Adults' page…

where teens, twenties and thirties write about life with a stoma.

I'm 24 years old and have had Crohn's Disease for 11 years. I have had a permanent colostomy for nearly five years. I also irrigate daily. Oh and I am a newly–qualified paediatric nurse. For my first article in *Tidings* my subject will be my job and how I manage with a stoma.

I began my job in February 2016. Being a nurse is a physical and emotional rollercoaster. My speciality is nursing children. A common response to this information is: "Ah, I bet it's nice looking after babies" and "Oh how lovely". I'm not disputing the fact that, yes, I care for some very adorable babies and some of the children I nurse are truly brilliant. But… people, at times, don't realise what else nurses do. We work long day and night shifts; I do 12½ hour shifts three to four times a week. Sure that might not sound too bad on paper – but trust me, it's exhausting.

We support, advocate and comfort both patients and families. We alert the doctors if a patient is deteriorating. We calculate and administer medications and many other treatments. We are the middle–person between the doctor and the patient, ensuring demands from both sides are met as peacefully as possible! In one 12½ hour shift, I feel I've run an emotional and physical marathon. Caring for a helpless baby one moment and then a vulnerable teenager the next – it certainly keeps the adrenaline pumping! There are many emotional, both happy and sad, moments in this profession but I have a huge amount of empathy for my patients as I have been through similar issues. There have, however, been moments at the end of a shift when I have questioned why I chose this career, particularly when I already have enough 'baggage' in my life!

When I started my job, the only people who knew about my stoma were in the occupational health department. I didn't tell anyone at work about Neville (my stoma) for the first four months as I felt there was no need; it didn't really impact on my work. I am a believer that being open about my stoma is important and I'm not embarrassed about discussing him when anyone asks. I will though admit I got very nervous when I decided I had to divulge this personal information to my ward managers. My shift pattern was becoming really difficult: lots of night shifts, which I find very tough on my body–clock. I therefore decided to ask my managers to reduce my night shifts.

They were completely shocked. They couldn't believe it. They praised me for just getting on with things despite having a stoma. Of course they were very happy to adjust my shifts, particularly when I explained to them that I irrigate after every 12½ hour shift, in addition to the 45 minute drive home. I felt very emotional after I told them. I'm not 100% sure why. I am an expert at putting on a brave face and people–pleasing. I'm not good at talking about myself to other people. I feel that so many people are going through horrendous times; why should I discuss my medical woes? But I am pleased I did share – I now have people at work who would understand if I had to take a sick day or had a stoma–related accident at work.

Talking about stoma–related accidents, I am very fortunate to say that, touch wood, I am yet to suffer a major problem at work with Neville. I have had a couple of near–misses when the bag filled up a little but luckily it wasn't too full so I had time to get to the bathroom. The bathroom at work is quite old and the loo doesn't flush well; later people noticed a certain unpleasant odour. I just kept my head down and acted all innocent!

As I mentioned earlier, I irrigate daily. It is tough after a long day/night shift to summon the energy to irrigate for an hour before crawling into bed. I do struggle and at times I really do wonder how long I will last in this profession as trying to manage my stoma whilst being a nurse is a fine–balancing act. But I have coped and can confidently say to anyone who is about to have a stoma or who has one, that you can 100% live the life you want and deserve. Yes, sometimes you need to step back and say: "Enough. I can't do everything and please people all the time." I think we can all relate when I say that putting your health first is a priority – we only have one body after all!

Molly

If you are a young person with a stoma and would like to have your say:

send an e–mail to
editor@colostomyassociation.org.uk

or a letter to:

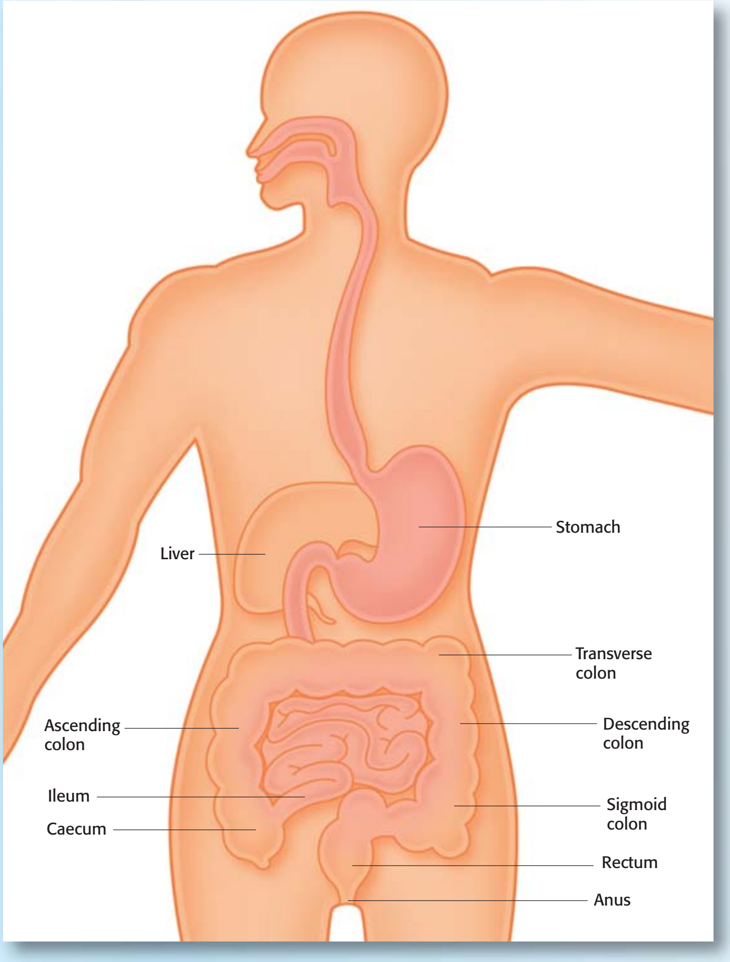
The Editor
Colostomy Association
Enterprise House
95 London Street
Reading RG1 4QA

Surgery resulting in the formation of a stoma

Jennie Burch

*Enhanced Recovery Nurse Facilitator,
St Marks Hospital*

There are a number of operations that may result in the formation of a stoma. The main ones are a Hartmann's procedure or an abdominoperineal resection of the rectum; also termed an AP, APR or APeR. An operation that results in the formation of a temporary ileostomy is a low anterior resection, also termed a TME which stands for total mesorectal excision.



The functions of the Gastrointestinal Tract

To understand the different operations it is important to appreciate the anatomy and function of the gastrointestinal tract or gut. This short biology update aims to help you better understand the operations.

Food is eaten and swallowed into the stomach. At this stage of the digestion process the stomach acids continue breaking down the food, which the teeth and saliva started. Then the liquid food leaves the stomach and travels down into the bowel also called the intestine.

The first part of the intestine after the stomach is called the small bowel. Here fluid along with most of the nutrients are absorbed from the food into the blood stream so that they can be used by the body. Anything that the body does not want moves from the small bowel into the large bowel also called the colon. The end of the ileum is the most common part of the small bowel used to form the ileostomy.

The waste that moves into the colon is much looser than the faeces that will eventually pass from the anus. The end of the small bowel called the ileum joins the large bowel or colon at the caecum near the appendix. The next part of the colon is called the ascending colon which runs up the inside on the right side of the abdomen. The colon then runs across the middle of the abdomen near the ribs; this portion of the colon is called the transverse colon and this part of the colon is used to form a transverse colostomy. The descending colon runs down the inside of the left side of the abdomen and is where a colostomy is often formed. The last part of the colon is the sigmoid colon and the gastrointestinal tract finishes with the rectum and anus.

Stoma formation

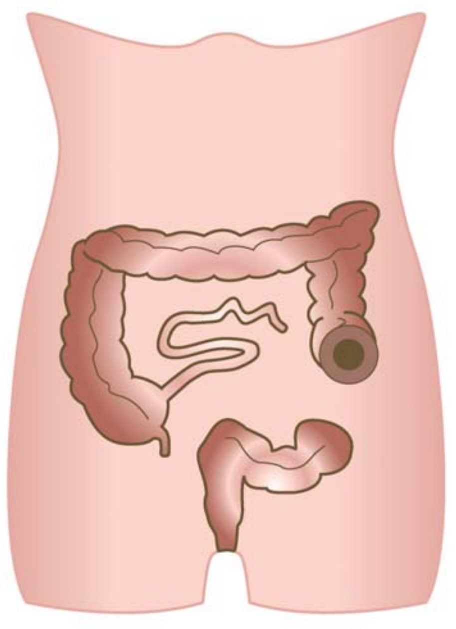
When a stoma is formed a small hole is cut through all of the abdominal wall: the skin, fat and muscles. The end of the bowel is then pulled through the hole and stitched in place. The stitches are dissolvable and will fall out a few weeks after the operation. If the colostomy is formed in the sigmoid or descending colon the output is generally formed faeces and wind. If the colostomy is formed in the transverse colon the output will be more liquid and it might be difficult to predict the bowel function in the first few weeks or months. In appearance the colostomy is red or pink in colour and to touch warm and moist but has no feeling. The size of the colostomy varies but it is usually round or oval in shape.

The difference between a colostomy and an ileostomy is that an ileostomy is formed from the ileum. The faeces that pass from an ileostomy are looser than from a colostomy. That is why the colostomy bag (appliance) is sealed or closed, to collect and contain the faeces and wind whereas the ileostomy bag is drainable. The ileostomy bag needs to be emptied several times a day; often four to six times, whereas a colostomy bag is replaced when there are faeces inside, perhaps one to three times a day.

Hartmann's procedure

A Hartmann's procedure is usually performed in an emergency situation for a perforated colon. This type of surgery is required most commonly to treat diverticular disease. Diverticular disease is the formation of small bulges or pockets that are called diverticula that develop in the colon. These diverticula can become inflamed or infected and this is termed diverticulitis, which may require treatment with antibiotics.

Diverticular disease is a disease that predominantly affects the older person, most commonly affecting the sigmoid colon. In rare situations one of these diverticula can split and faeces can leak inside the abdomen; this is life threatening peritonitis that requires emergency surgery. In this situation a temporary colostomy will be formed as it is unsafe to re–join the bowel when there is infection such as peritonitis present, as the join will not heal.



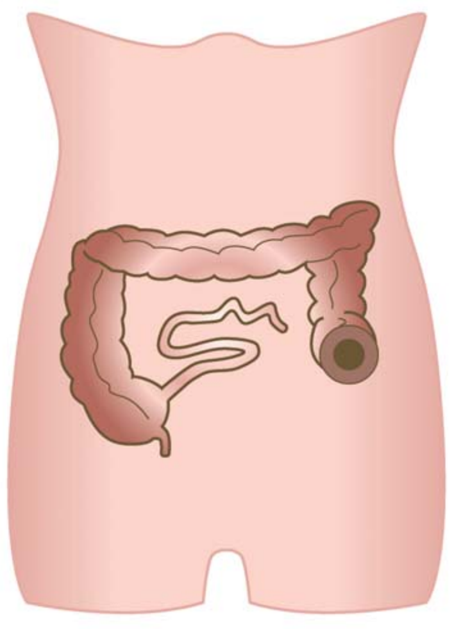
Hartmann's procedure

The part of the bowel that has perforated, usually the sigmoid colon, is removed. The rectum is usually left inside the body and the end is stitched over, so that any mucus made by the rectum will pass out of the anus and not into the body. The other end of the colon is brought out through a hole made in the left part of the abdomen to form the colostomy. This colostomy may be temporary; requiring another operation to reverse or close it.

Abdominoperineal resection (APeR)

An APeR is performed for many different reasons that include a low rectal cancer or an anal cancer. A cancer is a condition where the body cells, in this situation some of the cells in the bowel or rectum, grow and reproduce uncontrollably. Some of the symptoms that might make a person go to the GP with a bowel cancer are bleeding from the bottom, a change in bowel habit or abdominal pain. Cancers require treatment such as chemotherapy, radiotherapy or surgery to control the disease. Only the latter option of surgery, which is the main treatment for bowel cancer, will be explored here.

Before surgery it is necessary to have tests that include scans such as a CT or MRI, which can check to see if the cancer is confined to the bowel itself. When removing a cancer it is essential to remove not just the cancer but also some of the bowel around it, as this increases the chance of removing all of the cancer. After the operation the section of bowel that is removed is sent for testing in the histology department also called pathology department. This is where it is determined exactly what the cancer is and whether surgery is the only treatment needed or if chemotherapy or radiotherapy is also required. If more treatment is needed referral to see an oncologist is necessary.

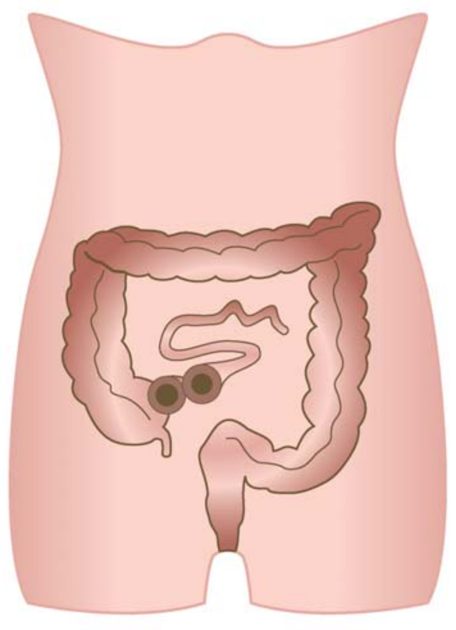


Abdominoperineal resection (APeR)

When the cancer is at the tail end; near the end of the gastrointestinal tract it is likely that complete removal of the cancer will damage the sphincter muscles that control bowel continence. If this is the case the operation that the surgeon will advise is an APeR. An APeR is the removal of the anus and rectum with the formation of a permanent colostomy, made from the either the sigmoid or descending colon. The colostomy is generally formed on the left side of the abdomen and will be permanent.

A temporary loop ileostomy

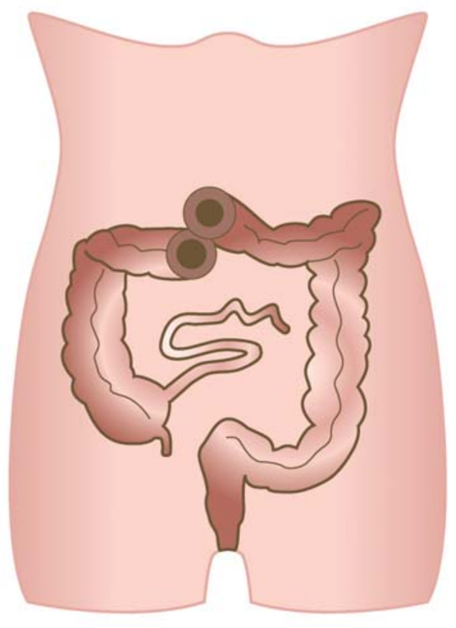
If there is a cancer higher up in the rectum that can be safely removed without damaging the sphincter muscles this may result in the formation of a temporary ileostomy, a stoma formed from the ileum. This allows the bowel around the surgery site to heal and the stoma may then be reversed at a later date.



A temporary loop ileostomy

Transverse colostomy

Sometimes a cancer may present as a bowel obstruction in an emergency situation. A bowel obstruction can present with symptoms of no bowel action, severe, intermittent abdominal pain, bloated tummy and vomiting. In this situation the surgeon might just make a stoma in the part of the bowel above the obstruction. This might be a transverse colostomy.



Transverse colostomy

Formation of a stoma may occur for reasons other than those mentioned but these are some of the more common operations that result in a stoma formation. Any queries can be discussed with the surgeon or stoma specialist nurse before the operation to ensure that details are specific for your situation.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From One Ostomate to Another

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

One Ostomate's experience of leakage

In my 25 years with a stoma I have to admit I've had a few leaks, mostly during the first few months when I was getting used to my altered plumbing. When I told my stoma care nurse about it she asked me to take off my pouch. She checked the hole in the flange was the right size for the stoma explaining that in the first few months the stoma shrinks and this allows faeces to come into contact with the skin causing it to become sore which means the flange won't stick securely. The gap between my stoma and the hole in the flange was no more than 1mm all the way round so she didn't think that was the problem.

She studied the back of the flange for any sign of the route the leak was taking and then the skin around my stoma looking for dips and creases, channels for the pouch contents to seep their way out. When I sat down she noticed a slight dip formed south-west of the stoma and when I told her that the leak was usually in this area she said that it was probably this dip that was allowing faeces to escape. She suggested using a convex pouch which has a slightly raised area of adhesive circling the hole in the flange, which adheres well and pushes the stoma out so that the output falls into the bag rather than working its way under the flange.

The reason I am not still wearing this type of pouch today is because after a few years I noticed slight bruising around my stoma and occasionally developed granulomas, the result of the hard convex flanges that were around in the 1990s. Today we have appliances with soft convex flanges so it isn't so much of a problem. However, it is always best to check with a stoma care nurse that a convex flange is suitable for you before trying out samples.

Another solution when the stoma is flat to the skin or has a depression or moat around it are flexible rings called washers or seals which can be moulded to shape and placed around your stoma before applying a bag with a flat flange. These have the advantage that if the dip is only on one side, as mine was, you can use just a small section of the washer.

How to apply a flange extender

Used by kind permission of Independence Products Ltd

Anyway, as it turned out my stoma care nurse said that the problem dip seemed to have filled out and suggested trying a flat flange again to see how I got on. I found that the thinner and more flexible the flange the better. For example the Microskin flange in the OakMed range is as thin as Clingfilm and follows the skin contours leaving no space for seepage underneath. After that I only had the odd leak, which were generally my own fault for changing in a hurry and not making sure the skin was perfectly dry before applying the pouch, or putting off changing so the pouch became more than half full.

I now have a routine which I carry out without even thinking about it:

1. Before putting the pouch on I push a finger through the hole in the flange and pull the sides of the bag apart to make sure they are not stuck together.
2. When the pouch is on I place my hand on top and feel for the stoma then run a finger around it to ensure the edges of the hole are firmly stuck down.
3. Lastly I fold back the pouch to expose the flange and run my finger around the circumference of the flange to make sure it's secure.

Now I can't even remember the last time I had a leak. Nevertheless, like everyone else who has a stoma, I still worry that it might happen at an important event or when I'm on a long journey with few 'comfort stops' on the way. Those are the situations where I use a flange extender (semicircles of adhesive designed to overlap the edge of the flange and stick on to the surrounding skin) to increase the area of adhesion. If faeces does manage to seep under the flange it has further to go to escape giving me more time to find a toilet. Flange extenders are good for occasions like this, but are not recommended for regular use, because if faeces regularly comes into contact with the skin it can become sore. Best to contact your stoma care nurse and she will assess the situation and suggest a better, more permanent solution.

Rosemary

Stomas are formed for many different reasons and come in all shapes and sizes so some people have more leaks than others.

Do you have any tips about coping with leakage to pass on?

Have you found a solution which works for you?

Are there any products which you have found useful in combating this problem?

Do let us know about your experience and how you or your stoma care nurse solved the leakage problem:

E–mail:
editor@colostomyassociation.org.uk

or

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

Looking forwards… not backwards

I have had irritable bowel syndrome for twenty years, my mother and sister have diverticular disease and my father died of secondary liver cancer which they thought came from primary bowel cancer…so bowel problems run in the family.

My mother had diverticular disease for over fifty years which resulted in two bowel resections. In May 2015, at the age of 78, she went for an operation and was told they did not know what they would find inside and she may end up with a colostomy. At this point I looked on YouTube to see how to change a colostomy bag in preparation for looking after her. The outcome of the operation was that my mother had a massive, benign ovarian cyst removed and no colostomy was needed.

After a week looking after her I returned home and back to work, then the following weekend drove for two hours to my son's to help the family move house. I raked up 22 bags of grass that had been left in the back garden then pick–axed a big ring of boulders and moved them to the bottom of the garden so my little granddaughters would not fall and hurt themselves. I felt a twinge in my abdomen and thought I had given myself a hernia but the pain settled and there were no lumps.

Monday I went back to my business as a self–employed cleaner but I was exhausted and had to take a week off sick because I could hardly stand up. I spent most of the week sleeping and by Thursday my irritable bowel had flared up. After a trip to the doctor we waited for the bowel to settle but by Wednesday the cramps were worse; I had barely eaten for a week and was just sleeping all the time, so my husband took me to A & E.

The nurse said a "rip–roaring" infection somewhere in my body had shown up in my blood test. The surgeon came and did the usual prodding and poking. At this point I realised I might need an operation and six weeks off work; as I am self–employed and normally work 51 weeks of the year this was a worry. After X–rays and a CT scan I was told I had a ruptured, and maybe resealed, sigmoid diverticular abscess. I also had leukaemia and that they could not treat the abscess as the leukaemia was already out of control.

I was taken to haematology and given 'soft' chemotherapy. Then the next day I was transferred to Coventry University Hospital where I would stay for a month in an isolation room receiving stronger chemotherapy and waiting for my blood to recover to safe levels. However, every time they stopped my antibiotics my temperature spiked and the antibiotics had to be started again. My consultant haematologist, Dr Borg, told me that the bowel was not going to get better and I needed an operation which would result in a colostomy.

If the leukaemia diagnosis and being signed off work for a minimum of six months wasn't enough of a shock, I now had to have major surgery and a colostomy! I cried more about having the colostomy than I did about having cancer. How ironic, after praying that my mother would not have cancer or a colostomy, two months after her operation I had both. I was told the colostomy would be temporary and if I beat the leukaemia I could have it reversed – little consolation at the time.

On 26 August 2015 I had a Hartmann's procedure and woke up to meet my new mate, 'Siggy' (so called as it was the sigmoid colon causing the trouble). It took several days before 'he' actually started to work and I began to panic about being sent home only having changed the bag once or twice. Mr Osborne, my surgeon, however, was very reassuring and with the help and support from Denise, Karen and Kim, the stoma nurses, I felt less worried knowing I could ring them if there was a problem.

I eventually got home seven and a half weeks after being admitted to hospital, but I felt like a stranger in my own home; not only did I have a colostomy which I was nervous about, but also a thermometer to take my temperature daily, in case I showed signs of infection due to the chemotherapy weakening my immunity.

After two weeks at home I was admitted for a week for my second course of chemotherapy, then was back home for a week before being readmitted with neutropenic colitis. Each chemotherapy would reduce the neutrophils (white blood cells that fight infection) and I would end up with an inflamed bowel and another week in hospital on antibiotics. The weeks when I had chemo (one session a month) 'Siggy' would stop working due to the anti–sickness medication causing constipation so I was prescribed Movicol which eventually worked. On Boxing Day 2015 I had my last bag of chemotherapy and by the end of January 2016 my bloods had returned to normal levels. I was in remission and told to live a normal life.

Although I'd had 'Siggy' since August 2015, I had spent a good deal of time in hospital therefore I changed my bag sitting on my bed with everything set out around me. I was still scared of having to change the bag in other people's houses or in public toilets.

My first time doing just that was at the cancer unit. I felt a strange sensation around my bag whilst I was sitting in a busy waiting room. I put my hand under my waistband and felt it was leaking. I was mortified and panicked rushing into the toilet in reception. As there was no hook I hung my bag over my back and tried to wash my hand, my clothes, clean up my stomach, take off the bag and replace it with a new one. All the while someone was rattling the door to get in and the nurse was looking for me to take me for my blood transfusion. Afterwards I sat having the blood, trying not to cry, feeling devastated and sorry for myself. Later I gave myself a stiff talking to: "Yes it was horrible but I dealt with it (badly) but no one died, so get a grip."


Warwick Stoma Care Team: Karen, Kim and Denise


Cathy carol singing on Ward 34 at Christmas 2015 (her last week of chemo)

I spoke to my stoma nurses a day or two later and discussed the issue of pancaking which plagued me. After trying different bags I have eventually found a convex bag that I trust and I have not experienced pancaking since. I like 'Siggy' and am fascinated and amused by him. After 20 years of irritable bowel, making sure I knew where every toilet was and panicking about getting there in time, 'Siggy' is liberating and I don't want him reversed.

I am still recovering from the effects of the chemotherapy so have not returned to work yet and have not needed to empty or change my bag in other people's houses. The thought makes me nervous, but I expect it will be fine. I still worry and walk around with my hand in my pocket to protect my stoma and in case the bag comes off, but with time I expect I will lighten–up.

I have no problem talking about having a colostomy. Anybody, and everyone who knows me, knows that I have one. My four and five year old granddaughters insist on checking him daily and stand watching me emptying or changing the bag, only complaining if it smells – which I remind them is the same for me if they ask me to wipe their bottoms.

As for the diverticulitis; every time I have abdominal pain for a day or two, I worry I will end up in hospital again – but, as with the leukaemia, I am well now and must live life looking forwards and not backwards.

I do know I could not have coped with 'Siggy' without the continuing support from my fantastic stoma nurses who remain ever patient with me, even though I bombard them with a barrage of questions on a regular basis. Thank you so very much Denise, Karen and Kim, also Dr Borg and Mr Osborne and all the hospital staff who kept me alive.

Cathy

Your chance to win up to £25,000 and support

colostomy association

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Unity is a lottery with a difference. We receive profits directly from the number of lottery players we recruit, so we need your support. For every £1 entry – 50p comes directly to the **Colostomy Association** as profit.

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If you have any queries please call our hotline on
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Results & Rules can be checked by visiting
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Calls cost no more than calls to geographic numbers 01 or 02.
You must be 16 or over to enter.

50p
From every £1 comes directly to us as profit.

The promoter of this Unity lottery is Colostomy Association, Enterprise House, 95 London Street, Reading, RG1 4QA I Registration number: LOT000141

Prizes

£25,000 6 digits	£1,000 5 digits	£25 4 digits	£5 3 digits

1. Your details (please print in block capitals)

Title:
First Name:
Surname:
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Postcode:
Tel:
Mobile:
D.O.B.:
If you would like to receive correspondence via email, please tick here ☐
Email:
☐ If you do not wish your name to be publicised if you win, please tick here

2. Payment Frequency

How many entries would you like each week? ☐

X

How often do you want to pay? (please tick payment frequency & write amount in box)
☐ Monthly/£4.34 Direct Debit only
☐ Every 13 wks/£13
☐ Every 26 wks/£26
☐ Every 52 wks/£52

=

Total Payable ☐

3. Select your Payment method

☐ Direct Debit

Please fill in the form and return to **Unity**
Name and full postal address of your Bank or Building Society.

To: The Manager: Bank/Building Society
Address:
Postcode:

Banks and Building Societies may not accept Direct Debit instructions for some types of accounts.

DD15

Instruction to your Bank or Building Society to pay by Direct Debit

Name(s) of Account Holder(s)
Branch Sort Code:
Bank/Building Society account number

Instruction to your Bank or Building Society
Please pay **Unity** from the account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this instruction may remain with **Unity** and, if so, details will be passed electronically to my Bank/Building Society.

Service User Number: 4 2 1 1 0 2
Reference:

Signature:
Date:

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16

Surname:
Date:

☐ Occasionally, **Colostomy Association** may send you samples and information that may be of interest to you. We do not pass on your details but may use them to keep you informed of what else is available. If you would prefer not to receive these, please tick the box.

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Calls cost no more than calls to geographic numbers 01 or 02.
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They will notify you of your **Unity** lottery number.

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Unity is operated by Sterling Management Centre Ltd, registered as an External Lottery Manager by the Gambling Commission under the Gambling Act 2005 – www.gamblingcommission.gov.uk

Be inspired!

Get your **Colostomy Association 2017 Calendar** today

How far have you travelled since having your stoma operation?

At the Colostomy Association, we believe that having a stoma should not stop people from living a full and active life, or from travelling the world. Discover incredible places with our beautiful 2017 calendar. Containing stunning scenic pictures from South Africa, the Norwegian Fjords, Greece, Florida, Belgium and Wyoming to name a few; how far will it inspire you to travel?

The calendar will look perfect on any wall or notice–board and it makes a great gift for friends and family. Each high quality spiral bound A4 calendar comes in its own white cardboard presentation envelope and costs only **£9.50** including postage and packaging. The calendar measures 420mm × 297mm when open and there's plenty of space to write in appointments. Best of all, in buying our 2017 calendar you are raising funds for a good cause.

All proceeds raised from the calendar will go towards supporting invaluable **Colostomy Association** services such as our 24–hour helpline, extensive range of free booklets and this very magazine you're reading.

Each month's image was submitted by a **Colostomy Association** supporter and our judges had a very difficult time shortlisting them down to the final 12 due the outstanding quality of all the entries. The winning photo of *Port Stanley in the Falkland Islands* was taken by Caroline Emeny and we think you'll agree it's simply stunning! This atmospheric photo takes pride of place on the front cover and also features as the picture for July. There are another 11 amazingly inspirational entries in the calendar, each perfectly suited for every month of the year. Caroline has received a large canvass of her photo for first prize, while the two runners up each received a free calendar of their own to use and as a keepsake.

Remember we'll need to know by 1 December 2016 if calendars are required in time for Christmas. So hurry to avoid disappointment as stocks are strictly limited.

Please allow at least 28 days for delivery and keep taking your holiday photos ready for the 2018 calendar!

Please send me [Quantity ______] **CA 2017 calendar/s** at the cost of **£9.50 each** (price inclusive of VAT & p+p). Please allow 28 days for delivery.

I enclose a cheque for £ ______ made payable to: **CA Commercial Ltd**.

Title:

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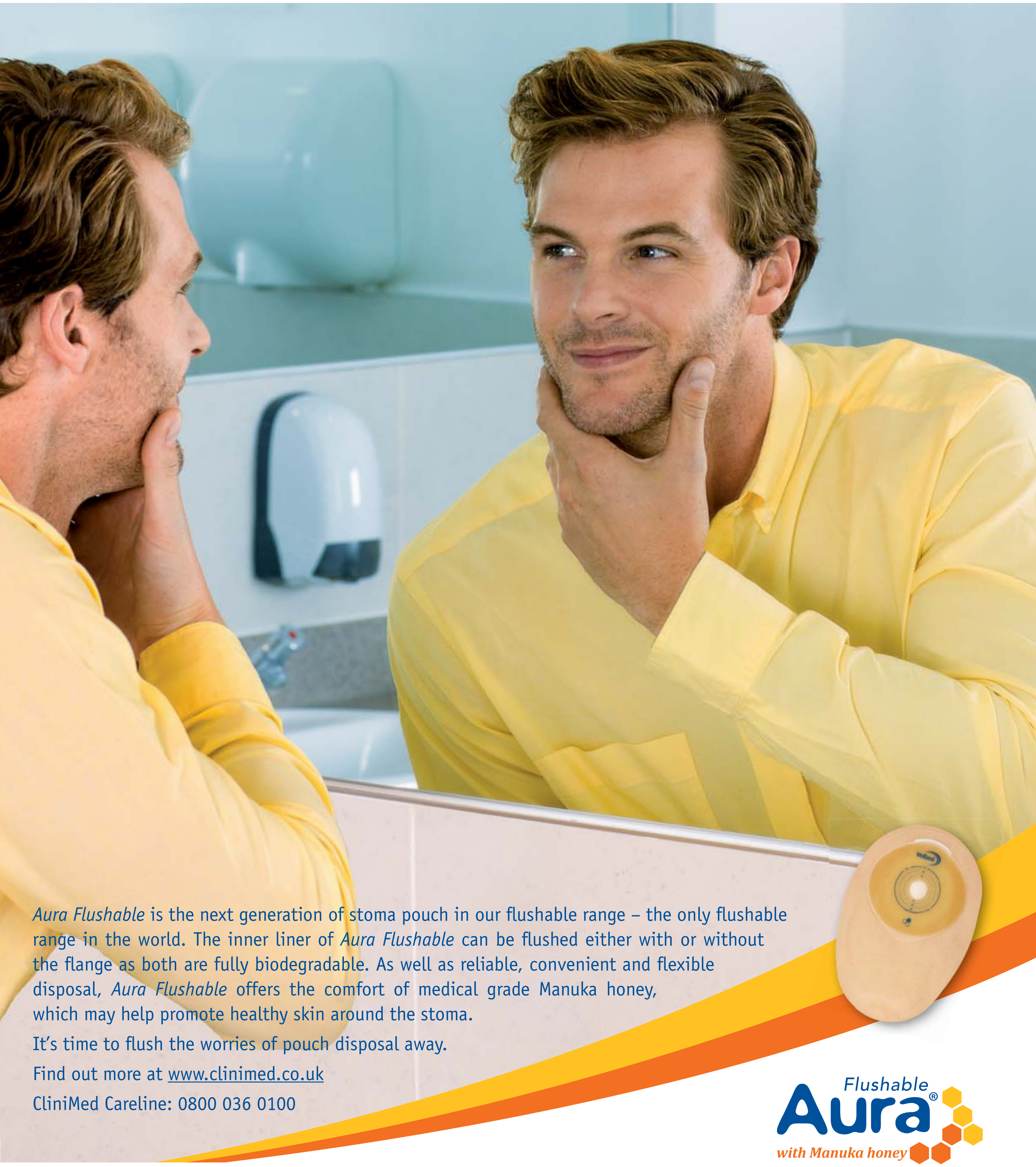
Colostomy Association, Enterprise House, 95 London Street, Reading RG1 4QA



We need YOU! Fundraising is an immensely **important source of income** for the **Colostomy Association** as we rely heavily on donations. Help us continue to provide **support to ostomates and their families 24 hours a day, 365 days a year.**

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

Charity of the Year Partners

The Colostomy Association is urging supporters and volunteers to help raise vital funding and awareness by asking their employer, school, association or club to make Colostomy Association their Charity of the Year.

Charity of the Year would be an exciting prospect for both the organisation itself and for the **Colostomy Association** as it allows two parties to come together to achieve great things. This partnership would greatly benefit thousands of people with a stoma, their carers and family members, and shows a commitment and dedication to social responsibility. Charity of the Year partnerships can take many forms and they are designed to ensure that both the company and the Charity benefit from the relationship.

- **Employee participation in our events**
- **Hosting a collection box**
- **Donating time by volunteering**
- **Encouraging employees to donate clothes and jewellery**
- **Holding a fundraising event**
- **Making a financial donation**
- **Donating gifts in kind**
- **Sponsoring an event**

Many people want to support charitable activities and, in our experience, this means that a lot of employees prefer to assist small charities where their involvement can make a real and visible difference. This often means that their staff have a 'vested' interest and engage more fully with charitable activities.

We would work with the organisation all the way to ensure their employees are supported and the company is publicly acknowledged by the charity. We take all our partnerships very seriously and work in a professional way to ensure that both the charity and the organisation mutually benefit from the partnership.

If you are aware of an organisation that may like to consider becoming a Charity of the Year partner or to develop an alternative bespoke partnership please initially contact **cass@colostomyassociation.org.uk** or telephone **Giovanni Cinque**, our Development Officer, on **0118 939 1537**.

Grant support

Several charitable trusts and foundations have been kind enough to offer us their support recently either as a contribution to the general running costs of the **Colostomy Association** or to fund specific projects. These include The Persula Foundation, Roger & Jean Jefcoate Trust, The Prudential PLC Small Donations Fund, The Vandervell Foundation, The Colefax Charitable Trust and The Peter Vardy Foundation.

Our thanks go to all of them for their highly valued financial support.

Caring for Colostomates

As this edition of *Tidings* goes to print we're nearing completion of our 'Caring for Colostomates' Pilot project that has been kindly supported by the Big Lottery Fund through Awards for All.

The project has delivered 24 workshops to family members, friends and carers who look after someone with a stoma as well as local support groups throughout Berkshire.

Over 300 carers have benefited from hands-on practical advice and guidance; the feedback from participants has been overwhelmingly positive. Jackie Dudley of the West Berkshire Ostomy Club said: "The comments brought back by the carers from your workshop today were so positive and delightful. They all felt it was well worth being there. They came away with a greater understanding of what their partners needed."

Plans are afoot to extend the project into further geographical areas in 2017 so watch this space or the website for further details.

Active Ostomates

Our Active Ostomates pilot project was also launched in 2016.

Funding from Sport England and the Berkshire Community Foundation has allowed us to produce our new 'Sport and fitness after stoma surgery' booklet which has proved immensely popular with individuals and health care professionals.

CONTINUED ON PAGE 21, COLUMN 1

CONTINUED FROM PAGE 19, COLUMN 3

They have also supported our regular Chair yoga sessions at the East Berkshire Ostomy Club which have been taking place since January this year.

There has been great feedback from participants, some of which are reproduced here;

> *"It has made me more aware of how my body is."*
>
> *"I wish we had this at every session!!!"*
>
> *"I find I am more relaxed for a day or so after the Monday session"*
>
> *"I tried to remember some of the breathing exercises when I was in hospital. To me it shows that if people were taught this when they first received a stoma it really would give them a tool for themselves, especially the relaxation, because of all the fears and anxieties."*

Plans are also afoot to extend Active Ostomates in the future so again watch this space or the website once funding is obtained.

Get your share of the jackpot!

We're delighted to announce that **Colostomy Association** supporters are coming up trumps through the Unity Lottery on a weekly basis.

Earlier this year the Unity Lottery replaced our 500 Club and it's been proving popular ever since. Members have the chance of winning a whopping £25,000 a week (plus a £2,500 donation to the **Colostomy Association**), as well as smaller prizes of £5, £25 and £1,000. It seems the odds of winning a prize are quite high as **Colostomy Association** participants are coming up very regularly!

It costs only £1 a week to enter and the **Colostomy Association** receives 50p for every £1 ticket sold. The next winner could be you!

For your chance to win BIG for as little as £1 a week, and to help the **Colostomy Association** at the same time, join up by filling in the form on page 16 You can also join online, view the rules and the results by visiting www.unitylottery.co.uk

English Channel Swimathon

In the last edition we told you about Pauline Morgan and Wendy Rogers and their efforts to swim the length of the English Channel from the comfort of their own swimming pools!

Well, we're now delighted to be able to report that they both successfully achieved their targets early in July and between them have raised nearly **£1,500**! Massive thanks to **Pauline** and **Wendy** for their amazing efforts, and to everyone who supported them.

Wendy Rogers

Pauline Morgan

Giovanni Cinque holds the cheque for the money raised by Pauline and Wendy's Swimathon

Accepting the Challenge

In a year where we've already had an amazing number of people taking part in all sorts of runs, rides and challenges, it's gratifying to see that there are still individuals coming forward to help support us.

Lianne Davies will be competing in a Tough Mudder event and Emma Brander will be competing in the Great Scottish run in October. We will let you know how they both got on in a future edition.

Thank You!

Every year hundreds of people donate or raise funds for the **Colostomy Association** and while we can't publicly acknowledge everyone we would like to say a special thanks to a few particular people in this edition:

- **Colostomy Association** Volunteer **Caroline Emeny** raised a princely **£815** through her annual music quiz
- **Neil Grenford** donated the **£50** prize his quiz team won as runners up in the Stockport quiz league cup final
- **Ken Denton** donated **£250** from the monies raised during his year as Mayor of Horwich in Bolton

Dear Readers

I had my colostomy in 2007 due to a fistula and it was supposed to be temporary, but the fistula turned out to be tricky to repair, so my stoma is now permanent. I began irrigating three months post op and it really is no exaggeration to say it changed my life. It was definitely the turning point in my acceptance of the stoma and put me back in control.

If you have any questions, comments or experiences of irrigation you'd like to share please send an e-mail to sarah.squire@colostomyassociation.org.uk or write to me at Colostomy Association head office

Sarah Squire x

Irrigation and You

In the last *Tidings* I encouraged people to write in with their irrigation experiences or questions so thank you to everyone who took the time to get in touch. I thought it would be nice to show some of the questions, along with the answers I sent back, as I'm sure others have similar questions. We also have an interesting account of travelling with an Irypump from Frank Healy.

I am a keen irrigator, but I don't have any medical qualifications so I can only answer from experience – any medical questions must be answered by your stoma nurse.

❖❖❖

Q: ***I have just read your article in Tidings. I had a colostomy operation six years ago due to diverticular disease and the stoma is irreversible. I'm interested in having a go at irrigation – how do I know if it is suitable and are you able to leave the pouch off for a period of time. Do I get in touch with the stoma nurse at first?***

A: Thanks for getting in touch. The first thing you need to do is speak to your stoma nurse. They will advise if you are suitable to irrigate, and if so they will teach you the process. In the UK we are not able to order the kit ourselves until we've had training by a stoma care nurse.

I tend to use a normal pouch "just in case" for peace of mind, although I rarely experience output. Many people use a tiny stoma cap or even the plug after irrigation. If you find you are able and decide to give it a go do get in touch with any more questions you may have. It's also worth having a look at the **Colostomy Association** website and maybe buying the 'Irrigation and You' DVD which is great for explaining the process.

❖❖❖

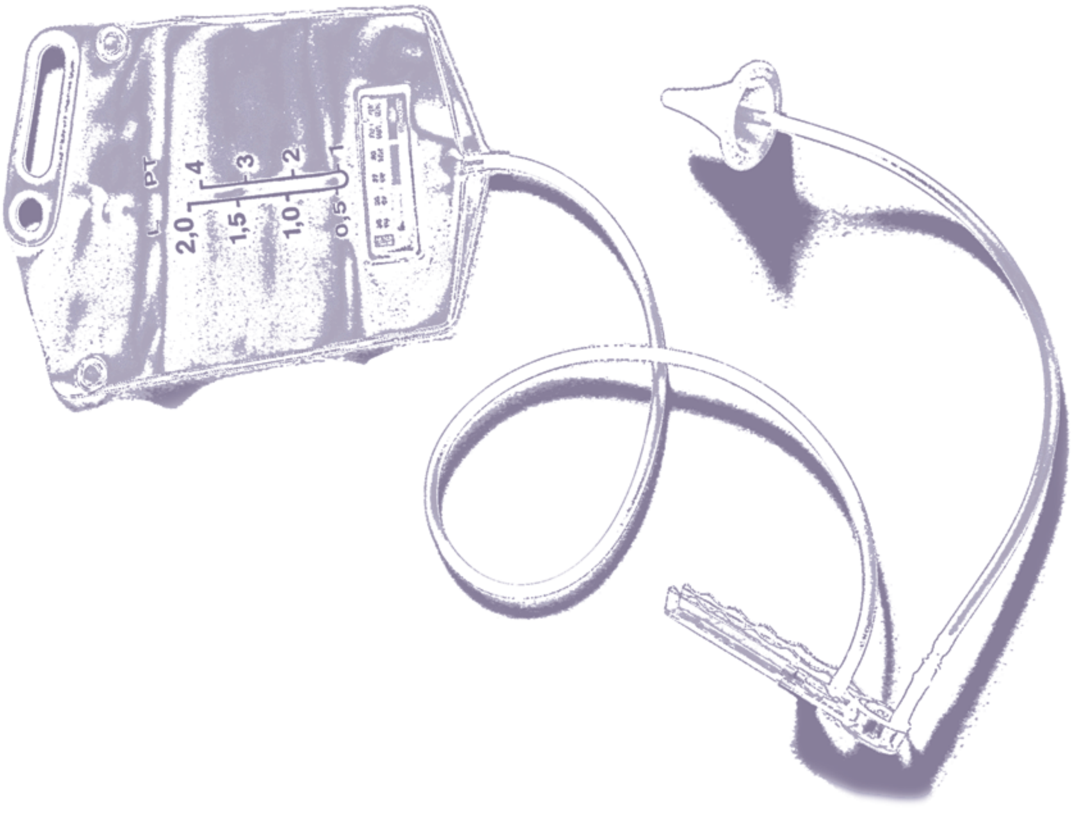
Q: ***I attempted irrigation for a year around 2006, however, it never really worked. I could not seem to get the full litre of water in and it would seep out as I tried. Much of the faeces would come out, but the stoma would activate as soon as I put the bag on and continue later in the day, so although the amount was reduced, I still needed to change the bag as often. Would a pump or any known techniques improve things?***

A: Thanks so much for writing in. As it happens I was sitting around a table of irrigators this morning at the **Colostomy Association** office so I put your question to the team. Our initial thoughts were that you may benefit from a second infusion of water once the first has expelled. I get a lot of output after the second infusion and it may be that the first infusion isn't quite clearing enough of the colon to stop breakthrough before the next irrigation. It's all trial and error, I'm afraid, as we are all a bit different. Also don't feel you have to instil a whole litre of water. I add water until I feel 'full'. You'll learn to work out this feeling for yourself.

We all felt that the pump probably wouldn't be a factor in making the procedure more successful for you. It may be worth making an appointment with your stoma nurse who may be able to help more on this as they will be familiar with your specific case.

❖❖❖

Q: ***I've just finished reading the Irrigation article in the Tidings magazine and have a few questions. I've been irrigating for about four months and from what I can tell it's going well. It only takes me about 20 minutes and I generally don't have any output in between. However, I do still suffer quite badly with wind. Last***



weekend I tried a cap as we're going on holiday soon but it just seemed to constantly inflate because of the wind. Is this anything to do with the length of time it's taking, as most articles I've read say it takes at least 45 minutes. If not, do you have any suggestions?

A: Thanks for getting in touch. I'm not sure I have the perfect answer for you though.

Irrigation often reduces wind – I'm not sure the length of the process would affect it either really. Be sure to check that the tubing is clear of any air bubbles, ie prime the tube with water prior to instilling as you don't want to introduce air into the colon if you can help it.

How about the foods you are eating? Do you tend to eat foods which are more likely to produce wind? Have you changed anything you eat or drink recently as diet is a real contributor to wind, especially things like chewing gum and fizzy drinks. If you smoke that can also be a factor which can increase wind. Unfortunately some people do tend to just be more 'windy' than others too.

Does the cap you're using have a filter? I stick to a normal bag after irrigation as I prefer the peace of mind, and the filter deals with any wind coming though. And I know some filters seem to suit some people better so it may be worth trying a different brand. How is it when you use a normal bag? Does that balloon? If not you might find it's better to stick with that on your holiday and perhaps fold it up to make it more discreet. I wish I could give you a definitive answer but irrigation isn't an exact science, I'm afraid!

Note: – I heard back from this lady a few weeks later and she had tried a different cap which seemed better so hopefully the issue was resolved.

❖❖❖

Q: ***When you fly, where should you keep your irrigation equipment? I've read it's best to keep it all as hand luggage, to minimise the risk of losing it, but do the bag and the tubes get picked up on the scanners? I have got my travel card just in case.***

A: Thanks for writing in. I always carry my gravity kit (and a spare) in hand luggage and in almost nine years of travelling with it have never been asked what it is.

Dorothy, one of our volunteers, who uses the Irypump, says: "I put my pump and the tubing in my haversack along with any other hand luggage which cushions it against damage. When presenting it for security checking, I always say this contains medical equipment and show my medical certificate. I have never had any problems."

❖❖❖

Dorothy would also like to thank **B Braun Medical** for the excellent service she received when two days before going on holiday her pump sprang a very bad leak which made it unusable. She phoned **B Braun Medical** first thing next morning and they arranged for a replacement to be delivered by courier all the way from Leeds to Nottingham that afternoon on one of the hottest days of the year.

CONTINUED ON PAGE 25, COLUMN 1

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CONTINUED FROM PAGE 23, COLUMN 3

Travel Hints and Tips

We always encourage people to travel with their stoma and not to worry about airport security. This is still very much the case but a handy tip has come from an experience by Frank Healy, Colostomy Association Trustee, volunteer and helpliner who recently travelled with his Irypump. Frank writes:

I am an irrigator and have a B Braun IryPump which I take with me particularly when going on holiday as you never know what facilities the hotel may have.

On a recent trip via Manchester airport I put my hand baggage containing all my bits and pieces together with my pump into the security tray and walked through the scanner without problem so proceeded to the conveyor to pick up my bag.

“Is this your bag Sir?” ”Yes” I replied. “Did you pack it yourself?” “Yes” I replied. “And what is this?” she asked, pointing to the Pump bag. I explained and handed her a copy of the Braun Pump travel certificate. “I will have to find my Supervisor” she said, and a few minutes later he appeared, swabbed the bag and put the swab into a machine. Someone else then took me to the X–ray scanner to scan my shoes.

I went back to my bag and the supervisor said: “I will have to ask you some questions” and led me off feeling like a criminal. He said the reason for their concerns was that my bag had shown evidence of chemicals and my electric Braun Pump definitely proved positive for chemicals being present.

My wife had joined me and said she knew what it could be. I had cleaned the pump the day before with sterilising tablets which contain a chemical. This was accepted as an answer but I still had to answer four A4 sheets of questions and sign a declaration that I was not carrying chemicals for any reason.

We ended up running through the terminal and only just caught the plane being the last passengers on board.

The moral of the story? If you clean the pump before travelling make sure you run plenty of water through it to clean out any residue that may have been left! ■

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. For more information see the **Colostomy Association** website or purchase the *Irrigation and you* DVD using the form below.

Colostomy Irrigation and You DVD

Order Form Colostomy Irrigation and You (Patients)

Colostomy Irrigation and You is an educational DVD aimed at patients, it has been produced by the **Colostomy Association** to raise awareness about ***colostomy Irrigation* as a method of bowel management. Note:** Not all colostomates have the potential to irrigate. It is therefore essential in the first instance to consult your Surgeon/Stoma Care Nurse as they will advise as to your suitability.

To obtain your single copy of *Colostomy Irrigation and You* at the special introductory price of £4.99 (incl postage and packing) simply fill in your details below and return it with your cheque made payable to the **CA Ltd,** to:
Colostomy Association, Enterprise House, 95 London Street, Reading, Berkshire RG1 4QA

Title:

Name:

Address:

Postcode:

Tel:

Email:

Please allow 30 days for delivery.

Colostomy Association, Enterprise House, 95 London Street, Reading, Berkshire RG1 4QA Charity No. 1113471 VAT No. 917079312

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

CUI WEAR®

New Innovation from CUI Wear

Welcome the new **“Adjustable Hole Belt”**

The new version of the **'CUI Support belt'** has been designed to meet the needs of patients when there is no other option other than to have a 'hole cut'

- With all the same features and benefits with standard Fulcionel Hernia Support Belt we have now developed a 'standard belt' available immediately with a 'pre-cut' hole that can be adjusted to fit around a wide range of stoma pouches and flange sizes.
- Simply place the hole around the stoma site and then secure in place by way of a Velcro fastening to the right size of the pouch with an easy action....& without the need to feed the pouch through!.
- Easier to put on, easier to access, easier to wear with comfort & confidence.
- Internal 'horseshoe shaped' anti-slip pad secures the area around the pouch acting to gently reinforce any pressure lost by way of the 'hole' itself - without over accentuating this.
- Left or Right sided belts available* (*when Velcro fastening is situated under the pouch)
- All belt sizes, depths & all 3 colours immediately available as standard requests
- Saves time of delivery and need to customise hole cutting

NEW Available on prescription from 1st September.

Hernia/
Abdominal
Support
Garments
Fulcionel®

Bespoke
Garments
made to
measure

Visit our new
website
www.cuiwear.com

Ostomy
Underwear
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Expert Support
Specialists
Nationwide

For more information please call our **Freephone 0800 279 2050**

COLOSTOMY DAY 2016

FIGHT THE POO TABOO

This year has been a huge success for **Colostomy Day** with more participants than ever before taking part in special themed activities across the country. Lots of people helped to fight the poo taboo and raised awareness by Making Some Noise or Staying Silent.

A special thank you goes to everyone who took part!

We hope you all had a great time on Colostomy Day and we look forward to reporting on your wonderful activities in the next edition of *Tidings*. In the meantime, please remember to put the date in your diary for 2017 – 7 October – and make this annual event even more successful year on year. Your involvement will help us break down the barriers and reduce the poo taboo!

A few examples of activities that took place are: ConvaTec and Amcare™ Group who encouraged people all over the UK to participate in 'Walk for Awareness' to support Colostomy Day. Jersey Ostomy Club who displayed a large banner on a dual carriageway and held a cake sale and Nisbys in Reading who sold purple cakes.

1967-2017

Colostomy Association Open Day 2017

A date for your diary

Make sure your calendars are marked with the Colostomy Association Open Day which will take place on Saturday 16 September 2017 at Wokefield Park, near Reading.

We hope you can join us for what promises to be an exciting day as we'll be celebrating 50 years by looking back to our original roots as the Colostomy Welfare Group. This special day will be a wonderful opportunity to find out about the latest stoma care developments, meet new people and help us celebrate our success.

The day will be packed with inspirational and informative talks, the chance to find out about the latest products from our exhibitors, make an appointment with a qualified stoma care nurse and much more. We hope you'll stay on for the evening and join us for an evening meal and ticketed Fashion Show, proving that having a stoma doesn't stop you from looking good and feeling great.


Steve Clark


Marlene Ellis

We're busy organising the whole day, having lined up keynote speakers, selected the models who will walk down the catwalk and have made sure that the event is informative, fun and memorable. We can't wait to see you there! More information about our Open Day and Fashion Show will be included in future editions of *Tidings* leading up to the event itself, so look out for further details.

Can you help?

Our Open Day will celebrate 50 years of helping ostomates and look back to where it all began with the Colostomy Welfare Group. As part of this we are looking to get in touch with family members of **Frances Goodall** and **Gertrude Swithenbank** who founded the Colostomy Welfare Group back in 1967. We'd love to hear from you if you can assist.

BREAKING NEWS…

- Asda has announced that they will be rolling out new signs for their accessible toilets in over 400 of their stores. The new signs say "Not every disability is visible". Great news Asda!
  - On the back of this, Morrisons, Sainsburys and Tesco are to meet with Crohns and Colitis UK to discuss their accessible toilet signage. We're working closely with Crohns and Colitis UK on this, who will also be discussing stoma friendly toilets on our behalf.
- The Association of Stoma Care Nurses (ASCN) has endorsed our *Active Ostomates – Sport and Fitness after surgery* booklet. The ASCN provide expert clinical resources for both new and experienced stoma specialist nurses. This ASCN endorsement means that patients can benefit from our booklet, safe in the knowledge that it has been accredited by this nationally recognised organisation.
- We're supporting 'Save Pangbourne Loos' in a bid to reopen their public toilets. If you know of any proposed public toilet closures, let us know and we'll help campaign to keep them

Colostomy Association Purple Iris Stoma Care Award

The Purple Iris is awarded for outstanding stoma care and exemplary service within a stoma care department or community setting and nominations are now being sought for next year. This beautiful award will be presented to the winner during our Open Day as part of our special celebrations.

The last recipients of the **Purple Iris Award** were the stoma care team at **Maidstone Hospital** (pictured left) who were presented with the award at our Open Day fundraising gala dinner in Reading in July 2015.

Judy Mallett and Kirsty Craven from Maidstone Hospital said at that time:

> *'We are delighted and honoured to have received the Purple Iris Award. We feel it is a very special achievement as the nomination has come from patients we have looked after. We believe passionately about providing a high standard of care for patients, their families and carers that we have had the privilege to look after'.*

Nominations are now open for the 2017 award, so if your team has gone above and beyond in their care for you or a family member please complete the form below and return it to us by **30 April 2017**.

We welcome nominations for stoma care teams who:

- **Deliver an exceptional level of care**
- **Lead an excellent co-ordinated care package with other agencies and across a variety of health issues**
- **Are innovative with their ideas to deliver outstanding patient support**

A representative from the winning stoma care department will be invited to attend our **Open Day dinner at Wokefield Park** on Saturday 16 September 2017 when an official presentation will be made by our President.

We look forward to receiving your nominations and to hearing about the wonderful work being carried out by stoma care teams across the UK. Careful consideration will be given to all entries and we will feed back comments anonymously to all nominated teams in recognition of their invaluable efforts.

Purple Iris Stoma Care Award – Nomination Form

Your details

First Name: **Surname:**

Address:

Post code:

Telephone Number: **Email:**

Nomination details

Name of team/department:

Name of hospital/community setting:

Reasons for nomination:

In two brief sentences, please describe what impact this team's support has had on your life or that of a family member (maximum 50 words) here:

Additional Information

On a separate sheet please explain why your stoma care team/department deserve this accolade (maximum 500 words). Please remember to head this up with your name and that of your nominee.

I give my permission for **Colostomy Association** to inform the stoma care team about this nomination including what has been written on this form.

Signed: **Name:** **Date:**

Please return this nomination form to: **Sue Hale, General Manager, Colostomy Association, Enterprise House,**
95 London Street, Reading, RG1 4QA by 30 April 2017.

Finding a New

The phone rang at 6am. I was in a hotel in Liverpool, the only night I was away on business throughout April 2007. Our daughter, Sarah, was due to give birth to her second child and I did not want my wife to go out alone in the night, to look after our granddaughter, Rebecca. Yes, my fears were justified, the phone call was to tell me Hannah had arrived in the small hours, and had only just managed to avoid the indignity of being born on the passenger seat of a Smart car!

At this point I had no idea that I was ill, but after the following May Day Bank Holiday I had a nasty stomach upset during the night but did not think much of it until my wife went ballistic at the state of the loo. I had no idea as I had 'flushed' in the dark but there were clear signs of blood, so I was ordered to the doctors post haste.

I did not really want to see my normal GP as she is the daughter of a near neighbour, so when I phoned for an appointment I was relieved to hear she was just about to start a six month sabbatical! I was offered a choice of two locums, one clearly a lady doctor and Dr Evans with an unpronounceable Welsh first name who I asked to see. For some reason I thought Dr Evans was a man so I was completely thrown when my name was called by a 40 something "blond". If I could have run away at that point, I would have, but a split second decision to accept the situation and go for it, was to stand me in good stead for what was to come.

Dr Evans very quickly came to the conclusion that I should see a specialist consultant and recommended Mr Goodman. I had been a member of my employer's private medical scheme for some time and we quickly agreed that we should use this rather than the NHS. On seeing Mr Goodman, he determined that I had a serious issue and set up CT and MRI scans and a colonoscopy, the latter carried out under sedation just after the Spring Bank holiday. While I was recovering he went to see my wife and told her that yes it was cancer, and yes he was positive he could do something about it but I would need to wear a 'bag' for the rest of my life.

As we recovered from the initial shock, my wife and I became determined to be positive about things and to do whatever it took to overcome the problem. It was at this point that the birth of Hannah became important to me as I wanted her and Rebecca to grow up and not only get to know their grandad but also to be old enough to remember me in the future! I also took the decision that I wanted to recover to go back to work so as to demonstrate that cancer could be overcome and it was possible to return to a demanding job that involved a considerable amount of travel advising major companies at senior level about the management and control of their insurable risks, and have a colostomy!

In the coming days it became clear that I faced a period of both chemotherapy and radiotherapy treatment running concurrently to reduce the tumour in size to make the subsequent operation easier. The treatment inevitability took its toll and the strain was not helped when the heavy rain and floods in July 2007 took out the water supply to much of Cheltenham knocking out the radiotherapy machines at the hospital for a few days!

The operation in October 2007 was a success. I had used the period after my chemo and radiotherapy to get as fit as I could, and I believe that this was a great help in my recovery.

At this point things took an unexpected turn. During the latter part of 2006 and early 2007, my employer had been consulting on and had then closed the final salary pension scheme. My future pension from this scheme would be based on my salary as at 31 March 2007. It became clear from the information provided that, if I chose to retire early, my pension would be adequate for my wife and I to live on. Why therefore should I go back to work?

On the 31 May 2008, I left employment and walked into the realm of retirement. What was I to do? My wife had given our daughter an undertaking some years ago that she would help with childcare when the time came, so during my recovery period I had been helping as best I could with the girls. Hannah was one of those babies who did not like to sleep, especially her afternoon nap, unless it was in grandad's arms. I have got to know the two girls in a way I did not know my own children at an early age, because I have been fortunate to have spent so much more time with them.

As nice as it is to do this, I still needed the challenge of something else! But what? I have always had an interest in railways and had intended to volunteer on a heritage railway if that was possible when I retired. I had joined the Gloucestershire Warwickshire Steam Railway, which runs in the lea of the Cotswolds from Cheltenham Racecourse to Toddington, when my wife and I had moved to Gloucestershire in 2003. I therefore looked to see if I could get involved there. Yes, it was possible and I joined as a Traveling Ticket Inspector (TTI), a job that involved traveling on the train meeting the visitors and clipping their tickets. As a TTI you are also responsible for both preparing the train before the day's service and cleaning up at the end of the day. I had learnt that it was from the ranks of the TTIs that volunteers were selected to become a Guard, a very responsible safety critical role on any railway. Here was my new challenge. So it was two years later I found myself on the platform at Toddington at 10:00am. Everything was set for departure and all that was needed was for the Guard to give the right of way to the driver. Then it dawned on me…that was my job!

While I have talked about cancer and my recovery, I had taken the decision at the outset that I would not talk about my colostomy unless I was asked and that is how it has remained. More recently two things have happened. I was asked to become a Director/Trustee of the independent charity that supports the railway, taking on the recruitment of the volunteers the railway needs to continue as a volunteer organisation, as unlike most other heritage railways we do not have a team of full time staff. Indeed, the work of the volunteers was recognised in June 2015 when we were honoured to be awarded the Queens Award for Voluntary Service. As Recruitment Director I have to have the confidence not only to meet with a large number of people on an individual basis but also to be able to stand in front of groups on a regular basis. To date, my colostomy has never let me down.


Philip being interviewed at the Air Power airshow in Austria in 2009

On the railway we are careful to ensure that those who hold safety critical roles are fit to do the job. Guards have to have medical examinations, and the railway's doctor was made aware of my colostomy and did not see it as a problem, as I feared she would. Sadly though, my eyesight has let me down. I am long sighted and have a lazy right eye which is showing signs of further problems, so 12 months ago I had to make the painful decision to hang up my Guard's hat. At least now I won't hear the public announcement I always feared: "We are sorry for the late departure of this train, the Guard is changing his bag"!

I also have a shared interest with my son, Jonathan. We attend air shows; my first with a colostomy was the Royal International Air Tattoo in 2008 where I had a ticket that allowed entrance to see the aircraft arrive and depart. That year it rained so much that the show itself was cancelled, but not before I had changed my bag in a very muddy car park. In 2009 Jonathan and I went to Austria together for a show. The day before departure if I could have got out of going I would have done, but on my return I said to my wife: "my colostomy is NOT going to stop me doing what I want to do".

So it was that the following year my wife and I travelled to New Zealand for six weeks, circumventing the globe and getting stranded in Los Angeles due to the Icelandic ash cloud! Important lesson here, make sure you factor in enough supplies in case you get delayed on your way home. As this magazine goes to press my wife and I, together with our daughter and husband are fulfilling a promise to take the girls to Disney in Orlando.

I am very lucky I have a well behaved stoma that I can manage, and which as I hope I have portrayed does not get in my way. My family are supportive and I have the inspiration of seeing the girls grow and recognition from them that I am the 'Best Grandad in the World'. I have the badge to prove it!

Philip Young

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.**

The new version of our 'CUI Support belt' has been designed to meet the needs for patients when there is no other option than to have the stoma pouch situated on the outside of the support garment.

The "Adjustable Hole Belt" takes away the fuss of 'feeding the pouch through' also providing a gentle reinforcement around the site of the hole generally lost when the hole is cut into a garment!

This new design is as easy to wear, as easy to manage and just as easy to live with as the standard CUI belts!

Ask your **CUI Support Specialist** for details or visit our new website **www.cuiwear.com**

* * *

The patented Stoma Protector was created by a fellow ostomate, who refused to allow having to live with a stoma prevent him 'living a normal life'.

View the video on **www.stomaprotector.com** and see how simple, how effective and, how comfortable **Stoma Protector** is to wear

Stoma Protector is designed to:

- Protect the stoma from pressure and impact
- Prevent leaks from the adhesive flange of the ostomy bag.
- Help prevent the problem known as pancaking.

Stoma Protector

living with confidence...

www.stomaprotector.com

Stoma Friendly Society

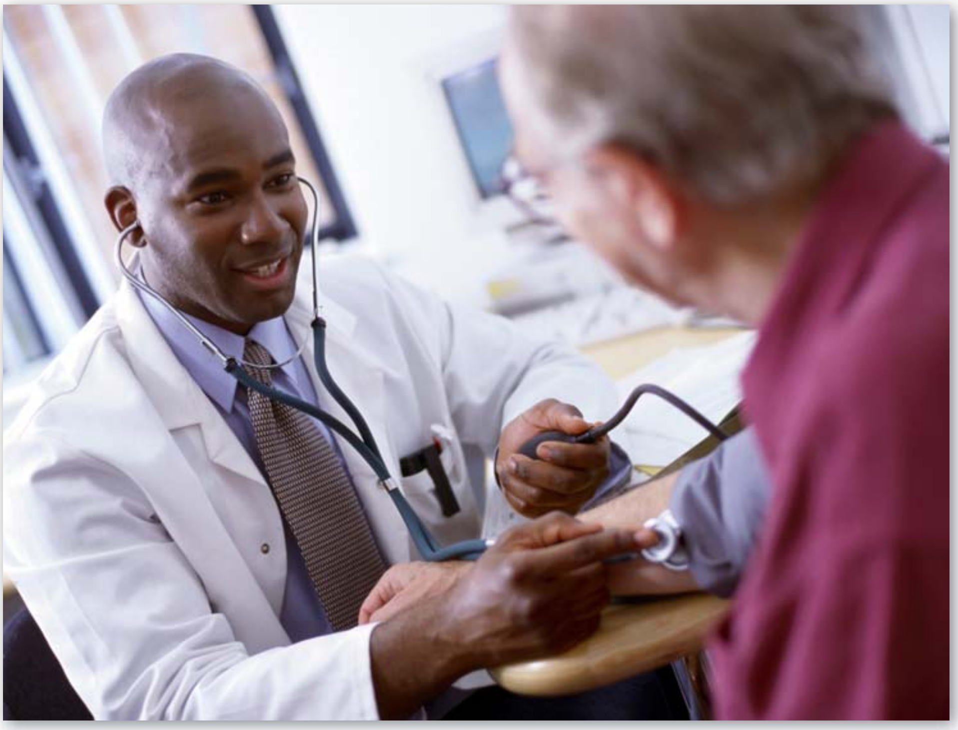
Our Stoma Friendly Society campaign continues to champion the rights of people who have a stoma to receive proper care and we are actively campaigning to ensure that facilities across the UK meet the needs of people who have a stoma. This includes working with businesses, public bodies and policymakers to improve toilet facilities and raising public awareness of the stigma many ostomates face when using accessible toilets, as well as educating airport staff on the issues and challenges faced during security searches. Workshops have already taken place at Luton, London City and Birmingham airports and an increasing number of organisations are making their toilets stoma friendly. We are partnering up with more UK wide organisations that are looking to make accessible toilets more inclusive for all users. By raising awareness with these campaigns, along with Colostomy Day and increased press coverage, we continue to #fightthepootaboo.

What's been happening?

- We are now a member of the **Care and Support Alliance**. The Care and Support Alliance was set up in July 2009 and represents 80 of Britain's leading charities campaigning for a properly funded care system alongside the millions of older people, people with disabilities and their carers, who deserve decent care. By joining the Care and Support Alliance we are part of a larger voice working for change and reform to the social care system for those we represent and the wider public.
- In May, Gwynedd Council proposed closing 50 of its 73 public toilets. Supporting local objections and protests, we wrote to the Council voicing our concerns. The Council now hopes it can halt its plans by asking the community and Town Councils to help fund public toilets in the county.
- The Association of Train Operating Companies (ATOC) have updated their Train Operating Guidelines. The new recommendations are for toilets to include a hook, shelf and disposal bin. The guidelines have been endorsed by the Rail Safety and Standards Board (RSSB), the Rail Delivery Group and The Department for Transport, and it helps specifiers and suppliers understand passenger requirements over and above compliance with existing standards. Over time this will mean that train toilets should become much more suitable for people with a colostomy.
- The Deep, one of the most spectacular aquariums in the world, is now stoma friendly. The Hull based aquarium has already won a number of awards for its accessibility and has now made changes to its accessible toilets to ensure they are stoma friendly. Visitors will now find a hook on the door, shelf space and a disposal bin in each cubicle.
- Based on feedback received from our supporters, letters have been sent to:
  - Eurostar asking them to make their toilets stoma friendly, both on the trains and on the platforms;
  - Manchester Airport offering their airport security staff a training session and seeking feedback on our Travel Advice booklet (in which they are currently mentioned); and
  - The Department for Transport and the Civil Aviation Authority thanking them for their support.

All in all, our **Stoma Friendly Society** campaign is going incredibly well and other developments are in the pipeline and we hope to be able to share these with you in **January 2017**! ■

The First Five Years after Cancer



Post–treatment follow–up tests

It's clearly a relief when treatment for bowel cancer is over, but for some people waiting for follow–up test results can be as stressful as the time they were first diagnosed. In this article **Beating Bowel Cancer** include some information from their leaflet *Managing Your Follow–up*.

After cancer treatment, follow–up tests are put in place over a five year period and are potentially life–changing. They can either reassure you that you are still clear of cancer or pick up any recurrence at the earliest possible opportunity so that treatment options can be considered.

What kind of follow–up tests will be offered?

This can vary from hospital to hospital. You may be offered a CEA (carcinoembryonic antigen) blood test, a CT scan, or both.

The National Institute for Health & Care Excellence (NICE) guidelines state that patients with primary bowel cancer who have had treatment to cure their cancer should be offered regular follow–up tests which may include:

- at least two CT scans of the chest, abdomen and pelvis in the first three years;
- regular CEA tests at least every six months in the first three years; and
- a follow–up colonoscopy at one year after initial treatment or sooner if you did not have one before surgery.

Your hospital team will follow local guidelines to ensure that you continue to be monitored in the most appropriate way for you. Hospital Trusts are looking to introduce differing levels of follow–up. Increasingly, suitable patients will be given the chance to opt in to 'self–managed' or 'remote' follow–up. This means that for low risk patients there will be no face–to–face appointments unless problems arise; only patients with complex problems will be required to come back to see the hospital team.

Test Anxiety

We know that the biggest fear for many bowel cancer patients is that your cancer may come back or spread to other parts of your body. Many people describe how they become anxious before follow–up appointments, and that going back for clinic appointments and waiting for test results can be very stressful. Even visiting the hospital again can create anxiety for some people.

Your colorectal specialist team will help you to understand your own risk of the cancer coming back, based on your original diagnosis and the type and spread of the cancer at that time. The follow–up tests described below will allow your hospital team to monitor your progress. If there are problems identified in these tests, this will trigger a review at a colorectal multi–disciplinary team meeting and further tests if necessary.

Follow–up tests

Scans

A CT scan takes a series of X–rays to make a cross–sectional image of the inside of your body, including the liver, lungs and other structures. Radiation is used during the scan, which takes about eight minutes and is painless. A dye, called a contrast medium, is injected into a vein for this procedure.

You will not be given other types of scans such as MRI or PET routinely during follow–up, however, these may be ordered if further images are needed in particular circumstances.

Colonoscopy

A colonoscopy is an investigation of the lining of your rectum and colon using a narrow, flexible telescope fitted with a tiny camera. It is an effective way of spotting problems inside the bowel lining and will be offered if you have any part of your colon left after surgery. If only your rectum is left, you will be offered a flexible sigmoidoscopy, which is a shorter scope.

If you have a stoma, the camera will be passed through the opening. If you use a closed bag system you will need to get some drainable bags from your stoma nurse to manage the increased fluid from the bowel preparation.

You can't have a colonoscopy if there is a serious risk of the bowel preparation causing you harm. If you have poor kidney function, you may have to be admitted to hospital for intravenous fluid support during bowel preparation. If you are taking warfarin, you will have to change to a different blood–thinning medication for a number of days before the colonoscopy.

Tumour markers and blood tests

CEA markers

CEA (carcinoembryonic antigen) is a protein made by some types of cancer including bowel cancer. Your CEA level can be measured by a simple blood test. CEA markers can be used by your doctor to monitor the response to chemotherapy, as well as often being used in the follow–up period when treatment ends. However, a CEA test cannot be used on its own as a means to diagnose bowel cancer, because not all bowel cancers produce the protein. So, some people who have bowel cancer don't show raised CEA levels at all.

Measuring CEA as part of your follow–up care becomes a useful test if your level was raised before the tumour was removed. In this case, a rising CEA level in the months and years following your operation could be an indicator of the cancer coming back. CEA can be a useful marker for detecting a new CEA–producing tumour, but a one–off raised CEA is not necessarily a sign of the cancer returning. Sometimes the CEA test is repeated to check that it wasn't just a blip or it might trigger scans in order to find out more. Understandably, any rise in your CEA level can cause a great deal of anxiety for you and everyone close to you.

Coping with your emotions

Waiting for scans and other test results can be a very anxious time. It's very normal to be stressed during this time and it can be very unsettling, even if you have experienced the same tests on previous occasions. You may experience 'butterflies in your tummy', a change in bowel habit, loss of appetite and other signs of anxiety. You may also feel more irritable or tired.

These symptoms can make you more anxious, especially if the physical response leads you to think this is linked with symptoms caused by your cancer coming back.

It's important to have a strategy for occasions like this, a plan of action to give you more control over your ever–changing emotions and to better fill your time with practical ways of coping. This won't necessarily take away the anxiety completely, but allow the experience to be less traumatic. It does take some effort and self–discipline.

You may experience changing emotions where one day you want to share and talk, and the next you want to completely banish all thoughts of cancer. Being mindful of this will help you choose your coping strategies, depending on your mood. Your loved ones may need some indication of this so that they can try and support you in the best way possible.

Unfortunately, there is nothing you can change in terms of test results, where waiting can feel like an eternity, and the desire to know now can leave you helpless and frustrated, but you can have some control. There may be things you can do to make this time more bearable:

Seek support from friends and family who will listen and allow you to talk!

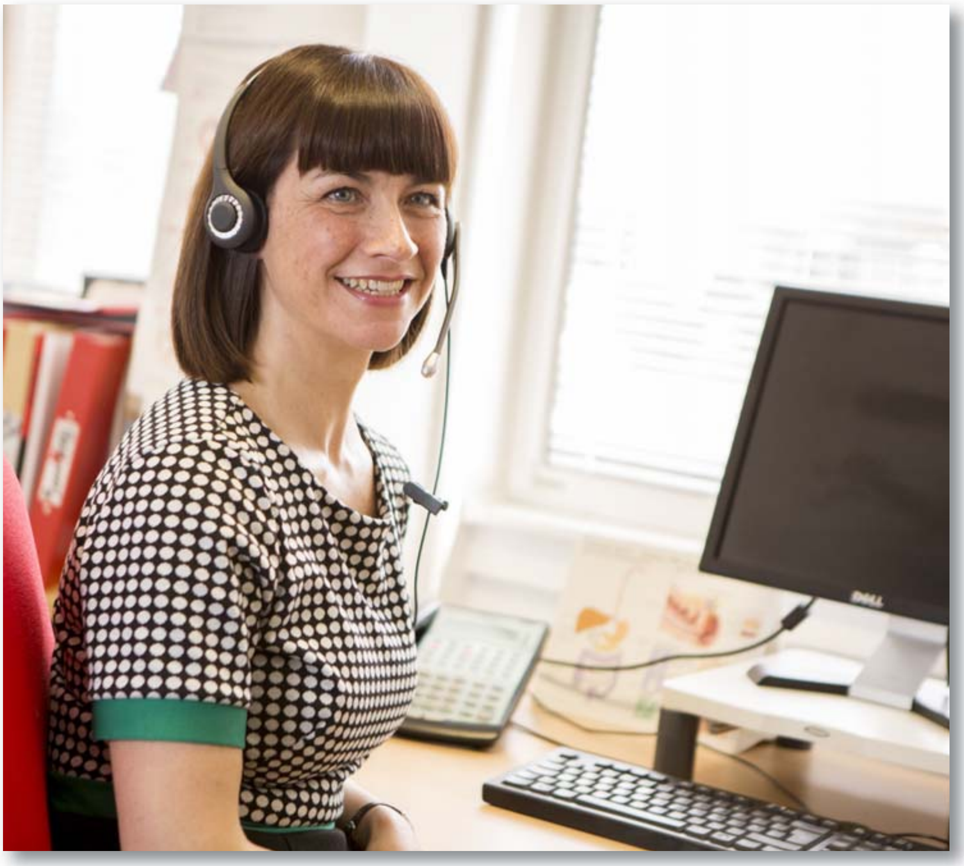
Talk through your concerns with the **Beating Bowel Cancer** nurses who can help you offload with someone very used to discussing these worries.

Let your colorectal nurse specialist or GP know if you feel your anxieties are overwhelming you. They can help, maybe with temporary medication or by offering you extra support such as talking therapies or counselling.

For some people, having a practical plan of action can be helpful. In the event of the news being bad, what do I plan to do? How will I cope? What concerns you the most… is it the thought of another round of treatment, or your job and paying bills if you are too ill to work? Sometimes breaking these fears down into chunks and dealing with them one by one can be helpful.

Find a support group, such as our online forum to share your thoughts.

Beware of too much internet advice. Your health is truly unique to you; trying to find out your result through the experience of others may actually confuse you and make your anxiety worse. For some, surfing the web can be really helpful, but if it makes you anxious, you may well want to avoid it



At **Beating Bowel Cancer** we're here for you and your relatives.

Please do get in contact with us:

phone our nurse helpline **020 8973 0011**

email **nurse@beatingbowelcancer.org**

or chat to others affected on our online forum on our website

For more information or to read the complete leaflet *Managing Your Follow–up* visit the website: www.beatingbowelcancer.org

Quality of Life Survey

Earlier this year a questionnaire was sent out to more than 22,000 people on the Colostomy Association database. A special thank you goes to the 1,307 who completed this Quality of Life survey. Not only will this valuable data enable us to improve our services, it will also enable us to ensure that our future campaigns and projects are focused on what really matters to you.

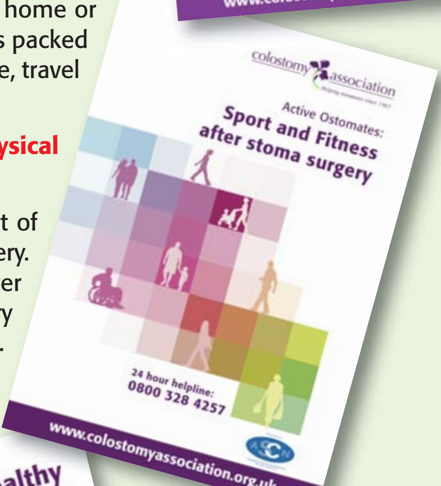
Here's a summary of the responses we received.

39% of people who completed the survey felt that having a stoma had restricted their ability to travel in the past year.

We realise this is an issue but planning ahead, carrying sufficient spare supplies etc. should help people regain their confidence, so they feel able to travel at home or abroad, whether it is for business or pleasure. Our Travel Advice booklet is packed full of information on flying, taking supplies, how to obtain travel insurance, travel certificates, NKS keys and much more.

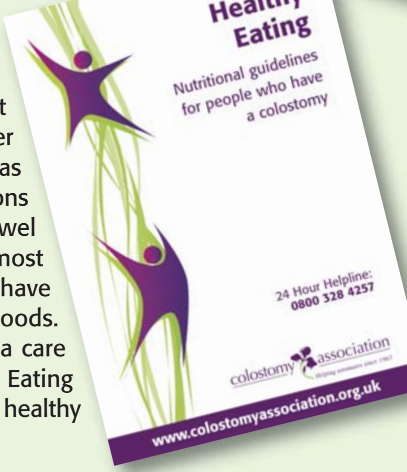
53% of respondents have had difficulty taking part in sports and physical activity in the past year.

Adapting to life with a stoma can be a challenging time and the thought of exercise may well be the last thing on your mind as you recover from surgery. But getting fit and being more active could actually be the key to a faster recovery and a better quality of life in the long run. With time, there is every chance that you can expect to return to a good level of fitness and strength. Our Active Ostomates booklet can guide you through a variety of gentle exercises and it also gives advice on returning to more physical sports.



59% of those who completed the survey felt their diet was restricted as a result of stoma surgery.

In the early days after surgery it is common to be concerned about how different foods will affect stoma function, but it is important to remember that as time goes by most people are able to eat a wider variety of foods. However, we are all different – stomas are formed because of a range of medical conditions and some operations involve removing more bowel than others. This means some people can eat almost anything and have no side effects, while others have found by experience it is best to avoid certain foods. Keeping a food diary can help you and your stoma care nurse assess what foods suit you. Our Healthy Eating booklet offers guidance on how to try to maintain a healthy and balanced diet.



The psychological impact of having a stoma on body image, confidence, mood and mental wellbeing were also of concern to 45% of respondents.

Our 24 hour helpline and closed Facebook group are there to help you. Please contact us any time you need to talk on the phone or chat online. We are here to listen and to support you whenever you need us.

Discrimination was another common issue for respondents. 33% of those using an accessible toilet had been challenged and 29% of travellers had experienced problems with airport security.

Please refer to our Stoma Friendly Society section for an update on our campaign and what we've been doing to champion your rights. Changing Places, The British Toilet Association and Crohn's and Colitis UK are also doing a great job in this area.

To obtain your copy of any of the booklets mentioned please download them from our website, email **cass@colostomyassociation.org.uk** or call **0118 939 1537**.

Some lovely feedback was also received from our respondents about our range of free services. It's always great to hear first–hand that our Charity is positively benefiting thousands of people each year. Here are a few of your comments:

'The Colostomy Association is a life line to me, through their Facebook group and *Tidings* magazine. I have also phoned them when I didn't know where to turn, I had a massive hernia and doctors wouldn't listen to me.'

'I enjoy *Tidings* – a lot of the articles are very good and inspiring.'

'I cannot fault the CA. Excellent Services. Great help when I first came out of hospital with my stoma.'

'Your magazine and fact sheets were very helpful in my early stoma years. Now, the medical articles and practical tips are good. Thank you, keep it up please.'

'Tidings is excellent and I always enjoy reading it.'

Thank you again to everyone who completed our Quality of Life survey – your feedback is very much appreciated. Sue B of Chester received the £50 Debenhams voucher in the prize draw.

Junior Ostomy Support Helpline (JOSH)

Meet our JOSH snow leopards

Our fluffy (JOSH) snow leopards will soon be making their way to paediatric departments across the UK thanks to grant funding. Nurses will be able to give these gorgeous cuddly animals to children who are about to have or are recovering from stoma surgery, or who have bowel and bladder dysfunctions. Along with a JOSH leaflet, nurses will ensure that parents and children know that they are not alone and that JOSH volunteers are there to support them.

Anyone can be affected by stoma surgery, regardless of age, and our Junior Ostomy Support Helpliners are able to provide support, information and reassurance to parents and young people who need someone to talk to.

Our JOSH team of volunteer parents give confidential, unbiased and practical advice on raising a child with a stoma, or a bladder or bowel dysfunction. We're able to pair any caller to a JOSH parent whose experiences best match their own.

If you need to talk call **0800 328 4257** and ask to speak to a JOSH parent. Anyone who now makes a JOSH enquiry will automatically be sent a JOSH snow leopard.

Aled Griffiths is our JOSH Children's Ambassador. Aled was born in 2003 with VACTERL association. Some of his anomalies include a hole in the heart, imperforate anus, one kidney, spinal defects as well as hand and arm issues. Aled spent the first eight weeks of his life in Southampton General Hospital where he had a colostomy formed at just two days old, followed by open heart surgery at the tender age of six weeks. As Aled only weighed 4lb 6oz, the stoma bag was huge in comparison to his little body.

After years of bowel and bladder operations and complications, at the age of seven, Aled had a further operation known as the ACE procedure. The operation was a success and allowed Aled to be fully independent. Aled has gone on to speak at various nurse conferences in front over 600 people, has been awarded a Rotary Young Citizen Award as well as a Diana Champion Volunteer Award. He is also the Children's Ambassador for the Mitrofanoff Support group. ■

Medical Terms Explained

ACE (Antegrade Colonic Enema) procedure

An operation where the appendix (or a section of bowel) is brought out through the skin to form a very small conduit stoma. This forms a channel into the bowel which can be catheterised to introduce water and a stimulant to wash faeces in the colon and rectum out through the anus.

Mitrofanoff procedure

An operation where the appendix (or a small section of bowel) is used to create a conduit (channel) leading from the bladder and out through the skin. This forms a continent stoma which has to be catheterised to drain urine from the bladder.

The breakaway Foundation

Celebrating 10 years
The Breakaway Foundation

Our tenth birthday year seems to be flying by. As I write this article it's already August and we are getting ready for our family weekend at the August bank holiday. We have lots of new families coming this time; it is always great to welcome new families and to see how they walk through the door on the Friday, a little scared, a little nervous, and then come Monday the weight has lifted, they have new friends that understand what life is like for a child with a bowel or bladder condition. They go home knowing that they are now part of the big Breakaway family, where there's always someone there to offer support whatever time of the day or night.

July saw our tenth birthday family Fun Day at Beaumanor in Leicestershire. It was wonderful to be able to celebrate at Beaumanor as the team there have been involved with **Breakaway** since the beginning, and have shared with us the triumphs of all the "I did it" moments, whether that has been on the climbing wall, the zip wire, the high ropes, or out in the canoes. There's been quite a few similar moments for the parents as well.

In typical **Breakaway** fashion the Friday was lovely and sunny, then we woke up on the Saturday and it was grey and overcast. As we got closer to Beaumanor the heavens opened, and then just when you thought it couldn't get any wetter it rained some more. It was so wet that we had to have a change of plans and the instructors arranged for the inside climbing wall to be opened so that at least people could keep dry. Luckily at lunch time the rain stopped and the sun came out. The afternoon was spent on the high ropes and zip wire, as well as bridge building in teams, all the bridges fared very well and no one fell in. We were delighted that Bullens, Salts and Trio were able to join us on the day, and the families that attended were able to see the products that they had on offer, including the long awaited new ACE stopper.

Looking back over the last ten years it's amazing to see how far the first **Breakaway** kids have come. One of them is a qualified nurse, one is now a Trustee of **Breakaway** and busy working in IT, one is sitting their 'A' Levels and planning to leave home to go to University, and one is busy planning their wedding which is in September. Hannah, who was the reason that **Breakaway** was founded, is now 15 and this time next year will be waiting for her GCSE results, sometimes it really does seem like the last ten years have flown by. The great thing is that they've all kept in touch and have been there to support each other through the ups and downs that invariably come with living with a lifelong medical condition. They are a huge inspiration to the current crop of **Breakaway** kids, and their parents, showing them that anything is possible if you set your mind to it.

More information about Breakaway Foundation.

Donate online via:
http://uk.virginmoneygiving.com/charityweb/charity/finalCharityHomepage.action?charityId=1008990

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

Stoma Aid

We are continually grateful to the hundreds of readers who have been donating their unwanted supplies to Stoma Aid. These items are making a huge difference to thousands of people's lives.

As well as product donations, a number of organisations have also offered financial help as we aim to continue to support people with a stoma in developing nations. Most recently, the **Rotary Club of Biggleswade** kindly donated **£150**, while **Warminster Rotary Club** has supported the project to the tune of **£100**. **The Farthing Trust** has also donated **£500** and these contributions will greatly assist this worthwhile project. If you feel able to offer a talk to your local club or have another avenue of fundraising for Stoma Aid, please let us know.

Mr Marie Shiferaw Tamirat's story illustrates what it is like to live with a stoma in a country where stoma supplies are not readily available.

Mr Marie Shiferaw Tamirat before the surgery

His son, Henok, writes:

My father is 54 years old and lives with his wife and five children in Gondar town of Ethiopia. He has been working as a high school biology teacher for more than 25 years. He does not go to school anymore after the surgery, which completely changed his life.

He has been sick for about a year. At first, the doctors at Gondar hospital thought it was constipation and they try to treat it with some medicine. However, there was no progress. The pain in his stomach and difficulty to excrete gets bigger. Later on, the doctors found out that he has colorectal cancer and he has to undergo a surgery and chemotherapy sooner.

He had the surgery about four months ago. The surgery looks successful to save his life. He is now on chemotherapy. He has done three rounds of chemo so far. The colostomy he has is a permanent type. The doctors found that the cancer grew around 10cm from the rectum and they said there is very less chance to use the rectum again.

The cancer treatment in Gondar hospital is new. People used to go to the capital, Addis Ababa, to get cancer treatments. Now, things look better at the hospital though not good enough.

There are a number of colorectal cancer cases and a number of colostomy surgeries done every year in Gondar hospital. However, people are less aware of colostomy bags. It is possible to say the patients know nothing about such bags and even the doctors seemed to forget colostomy bags exist. Doctors do not prescribe colostomy bags at all. Patients use shopping plastic bags to receive the faeces.

My father, like the other patients, fastens the plastic bag with a tape to his abdomen, just like the nurses at the hospital showed him. He does this three to four times a day. Using plastic bags has many problems on the patients.

The tape detaches easily. Especially when he walks, the movement of the abdomen muscles loosens the tape and detaches it. Therefore, he always needs to support the bag with his hands over his clothes when he goes out. If the tape detaches, the faeces will cover all his body. One day he went to mourning ceremony at the neighbours. The tape, which tightens the bag to his abdomen, was loosened on his way. While he was sitting there with the people, the faeces came in pressure and burst the tape in the middle of everyone. He came back home hurt and broken.

It is very difficult to attach the bag to the abdomen all round tight even if he uses the entire roll of a tape. There is always an opening through which gas escapes. The smell is unbearable that he cannot eat, sleep or go out with friends. Even at home, he remains at his bedroom fearing he may disturb his family if he comes to the living room.

The plastic bags available are transparent. Seeing everything happening in there hurts him a lot, it disgusts him. He always thinks, "Will I be able to live like this forever?" Sometimes it even makes him wish he die soon.

He changes the bags up to 30 times a week. The tape irritated his skin and the skin is starting to wound. It is very painful to use tapes over the irritated skin and now

Stoma Aid

he is being forced to use cloths like a diaper and remain at home all the time.

Above all, in a country like Ethiopia, where social life is very strong, where you live in an extended family which includes many people, where the people at the 20th block from your house, three miles away from your house are still your neighbours and you have to visit them, where you spend probably a quarter of your day visiting friends and relatives; it is very difficult to live detached from society. It feels like you are already dead.

With all these challenges he started wondering if there is anything special prepared for colostomy surgeries. He learned about colostomy bags on the internet. However, it was very difficult to find colostomy bags in pharmacies in Ethiopia. The pharmacies do not have them for a reason he cannot even guess. It is also complicated and unaffordable to get the bags from international market with his monthly salary of £150.

He has come to know some people with the same problem while he was in hospital and whenever he goes there for a chemo. Not one of them has access to colostomy bags and many of them do not even know they exist. They desperately need someone to aware them about the bags, provide them the bags and show them how to use them. Their life would be much easier with the bags. They can start living with families and friends again.

Henok Marie Shiferaw

How Stoma Aid is helping in Ethiopia

Sandra Kemp, a nurse from Leicester, who has been visiting Ethiopia for 19 years to work as a volunteer in Gondar Hospital contacted the **Colostomy Association** to ask if we would be able to help. After speaking to Sandra and hearing this story the **Colostomy Association's** Stoma Aid project in Bolton was able to arrange for suitable supplies to be sent to Sandra in Leicester. Sandra then arranges for them to be delivered by volunteers travelling to Gondar.

How you can make a difference

You can help make a difference to thousands of people across the world who cannot afford stoma supplies by either donating supplies or making a financial donation. Please send supplies you genuinely cannot use to Stoma Aid

at the following address:

Dean Philps
Stoma Aid
c/o Stone Logistics/PRS Limited
Lorne Mill
Lorne Street
Bolton
BL4 7LZ

Stoma Aid will accept the following:
All types of stoma appliances for adults and children including:

- Closed bags
- Drainable bags
- One piece bags
- Two piece bags (must include matching baseplate/flange)

Additional Products (which must all be at least 6 months in date):

- Absorbent gels
- Adhesive remover wipes, sprays and swabs
- Aerosols (spray and pump)
- Cleaning wipes, barrier wipes and dry wipes
- Dressings and bandages
- Frames and flange extenders
- Night/drain bags
- Pastes/creams
- Powder
- Seals, rings and washers
- Support belts, briefs and stockings

Stoma Aid cannot accept syringes, deodorants, prescription medications or drugs of any kind.

Stoma bags do not need to be in date but all accessories must be at least six months within their expiry date. Additionally, all two–piece donations must have both the stoma bag and matching baseplate/flange.

The cost of sending unneeded supplies to Stoma Aid can be reduced by using Hermes which has over 4,500 collection points across the UK. Prices start from as little as **£2.70** per parcel and more details can be found about the locations of their Parcel Shops on their website below (or by telephoning the **Colostomy Association** office with your postcode):
https://www.myhermes.co.uk/parcelshop–finder.html

Remember, help the NHS save vital funds – please do not over order supplies or over–stock items. Only send items ordered from the NHS in good faith that you now find that, for whatever reason, you cannot use.

Haven't got any supplies to donate but would still like to make a difference? Why not make a financial donation to Stoma Aid? (Please make all cheques payable to Stoma Aid and send them to the **Colostomy Association**, Enterprise House, 95 London Street, Reading RG1 4QA. **Thank you!**

Clothing Collections

Your unwanted clothes could help us raise valuable funds for the free services that we provide. **Colostomy Association** is working with **iCollectClothes** who arrange a time and place convenient to you to collect your clothing donations. A way of donating without parting with money.

If you live in **London, Essex, Kent, Hertfordshire** and **Suffolk** areas, you can put your unwanted clothing in your own bags or boxes and then book your collection on their website; an operator will call and arrange for a time and place for picking up your items. Visit their website at:

www.icollectclothes.co.uk or email: **info@icollectclothes.co.uk**

Alternatively, you can telephone **0844 879 4417** and arrange for your clothing collections to picked up at a convenient

What we accept

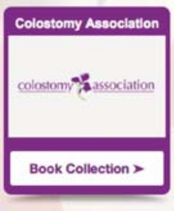
- ✔ Clothes (womenswear, menswear and kidswear)
- ✔ Paired shoes
- ✔ Linen, bedding, towels, curtains
- ✔ Accessories (bags, belts, hats, scarves etc)
- ✔ Books, DVDs, CDs
- ✔ Soft toys

What we DO NOT accept

- ✗ Sorry no duvets or pillows please

Please note! Your items MUST be in a clean and a suitable for reuse condition!

Remember to choose Colostomy Association for your donations



SASH

Freephone
0800 389 3111

Ref. No. HB102

Stoma Support & Hernia Belt *Ref. No. HB102*

The SASH Stoma Support and Hernia Belt is designed and manufactured by an Ostomist and gives support to the muscles surrounding the stoma.

Used by ostomists with a parastomal hernia (a bulging around the stoma) to help prevent muscle damage and enlargement of the hernia.

Eliminates most leakage problems and gives added security and confidence. Ostomists report relief from dull aches and pain in the stoma region when wearing the belt.

Ideal for work, sports, gardening, housework, DIY, or at any time stomach muscles require a firm support.

With support from a Sash belt and periodic consultations with a consultant some Ostomists are delaying, maybe permanently, the need for hernia surgery.

Ref. No. SR103 *"The ring of confidence"*

CUSTOM MADE BELTS ARE AVAILABLE ON PRESCRIPTION
No fittings required. Belts are processed and mailed within two working days

Security & Leakage Belt

This lightweight unobtrusive belt is designed to help eliminate leakage problems by holding the adhesive section of the pouch against the skin during all activities.

The belt also gives added security against the pouch becoming detached and will help to support the weight of a full pouch.

Ref. No. SS104

Stoma Shield *Ref. No. SS104*

The Shield will help protect the stoma from accidental chaffing or knocks.

Ideal for sport, gardening, DIY, housework, manual workers, builders, etc

Sash Medical Ltd.
Woodhouse, Woodside Road, Hockley, Essex SS5 4RU Tel: 0044 (0)1702 206502
Web: www.sashstomabelts.com

Facebook Meet – *Huntingdon, June 2016*

The CA Facebook group continues to grow and flourish, and in June this year some members met up in Huntingdon at an event hosted by Dansac.

Sarah Squire, Trustee and Facebook Admin writes:

The CA Facebook group members often arrange to meet up around the country for an informal get–together but group admins try to arrange an official group meet once or twice a year too. It really is lovely to meet up with friends old and new. And I don't use the word 'friends' lightly – many group members have become lifelong friends over time, while we all help each other out with stoma issues, share the bad days, but also laugh at the good times. The group is still an amazing place to come for support, but to meet up in person is the icing on the cake.

As with previous meets, much excitement and planning goes into an event and we are very grateful to Kirsty Stronge, Education Coordinator at Dansac, for the groundwork she put in to plan our day. Volunteer CA Facebook admins, Ian Jackson, Michael McCaughey and Sally Armstrong, joined me and 25 group members for the meet. Admin Steve Clark was unable to attend this time but was chipping in via Facebook as much as he could!

We all met up at the Marriott Huntingdon hotel and a coach collected us at 12noon to travel the short distance to the Dansac office in St Ives. As we arrived in the car park it was lovely to see a welcoming committee on the steps to the office – or so we thought. In fact there was a problem with the door and nobody could get into the office! Security had been called so while we waited, the buffet lunch was set out on tables on the grass and we had an impromptu picnic.

It was actually lovely to eat outside and I must admit I have never seen such a fantastic buffet. As my Gran would say, "Lovely spread". While we tucked into our sandwiches, sushi, fruit skewers, cakes, and chocolates, the Dansac staff were trying to find a solution to the locked up office. They didn't manage to fix the problem, but had arranged a room for us back at the hotel so by the time we had eaten and travelled back in the coach, they were ready for us all. I'm sure a few frantic phone calls had taken place but from our point of view it ran very smoothly and we are very grateful to Dansac for sorting it out so quickly.

Back at the hotel we were introduced to members of the Dansac team. Paul Newman, Education Director UK, began with an overview of the company, how it began and where they are now. We discussed products and a few group members suggested improvements they would like to see as patients. I think the good thing about getting a group of us ostomates together is that we are very honest about what works and what doesn't, as let's face it we live it 24/7 so we are the real experts! Next, Mope Alo, Marketing Manager, led a discussion about the use of social media in stomacare and we were able to explain to Dansac the incredible support our members have found through Facebook. They were keen to hear our thoughts on social media and how we would like to see it used throughout the stomacare world. Also joining Dansac were Steve Dudman–Millbank, Sales and Marketing Director Ostomy; Laura Savage, Customer Service Team Leader; Gabriella Baffa, Customer Service Advisor and Jules Plumb, Senior Territory Manager. Kerry Fearnley, Associate Product Manager, also came along to help with the door situation so many thanks to her for rushing to help!

Following the afternoon's discussions we took a break when a few members went for a swim, some of them for the first time since they had a stoma. We did think about trying to break the record for the number of ostomates in a pool at the same time but we reckoned The Breakaway Foundation and their kids probably beat us hands down as they all pile into the pool at their events!

We met again at 7pm and Dansac kindly covered the cost of drinks then dinner, and we were joined by Jules from their team. Group admins and Dansac had donated prizes for a raffle, including a special edition Tomas Bear who has become the group Mascot. Admin Michael won him but having already won a Tomas at our Cardiff meet last year, he decided to auction him, the highest bid coming from local man Ron Watson.

Proceeds from the raffle and auction, plus the kind donation from some members of the deposit paid to secure their place on the meet meant we raised **£300** for the **Colostomy Association**. Thank you to everyone who bought tickets and donated. Not only did we get to meet up and have a great time, we raised funds too!

Many thanks again to Dansac for a great event. And to those who haven't been to a Facebook group meet yet, keep your eyes peeled on the group as we are already planning the next!

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.

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.

Q: *I had my colostomy in 2005 and always had discomfort from a small (5cm) rectal stump. However, it became worse last year, waking me at night. My gastroenterologist organised for me to have a proctoscopy in November and they reported that it was inflamed and prescribed Prednisolone 5mg suppositories twice a week. I had a further proctoscopy in March and they said the inflammation has gone but as it is still causing discomfort I was told to increase the Prednisolone dose to three times per week but the discomfort hasn't gone. I was also prescribed Buscopan 10mg tablets but they didn't help.*

I just wonder if other people with this problem have found any other way to deal with the pain. I know I could have surgery to remove the stump but would rather not go down that route.

A: When you have a rectal stump you can get something called defunctioned colitis and this is an inflammation of the unused rectal stump. It is treated with steroids; this usually settles the inflammation which is obviously the case in your situation. If the discomfort has not settled even though the inflammation has gone then I would suggest a review with your consultant, it may be that they can offer something else or it may be that they do suggest surgery to remove the rectal stump.

Q: *After four years living with an ileostomy due to colon cancer I have weathered the usual mishaps and problems. I soon realized that the well-meaning advice: "You'll soon get back to your usual diet" was not true. I ate a fairly high fibre diet. Now my favourite foods are off limits. Greens, oats, nuts, pulses, wholemeal anything, causes loose output and ballooning, I miss them.*

My main problem is odour. When my granddaughter lay with her head on my lap and said she could smell drains, it was awful. I've tried samples from numerous companies, all to no avail, nothing works 100%. I'd be grateful for any feedback. Have any other ostomates found a way of dealing with this problem?

A: Odours can be caused by the food that you eat and therefore a food diary is a good start to try to identify the culprits and then you can choose to avoid them. You can also try things such as peppermint, either as a tea or a cordial; fennel as a vegetable, a tea or a mint and also charcoal as either a tablet or a biscuit. This little tip came from a group of my own patients who did some of their own research and identified that these three foods/drinks actually helped to reduce the amount of 'wind' they passed and also the amount of odour they suffered. You may also wish to try different pouches until you find one that gives you a filter that controls the odours to your satisfaction. Hopefully you will find a solution which suits and can then feel more comfortable in yourself.

Q: *Is Microlax OK to use when one has a stoma?*

I'm thinking of times where it would be prudent not to need to be running to the loo to attend to my stoma – long flights for example. It's really annoying when my system decides to get active and the captain has the seat-belt sign on!

A: You do not state what sort of stoma you have, if it is an ileostomy then you should not be using any sort of enema, I'm presuming that when you say Microlax that is what you are talking about. Microlax enemas can be used with colostomies but should not be used as a method of controlling the bowel action. They are for use when you have been diagnosed with constipation. If you do have a colostomy and are concerned about when and where your stoma works then it may be worth you speaking to your stoma care nurse so that she can discuss other options with you, for instance stomal irrigation or the use of the Conseal Plug. These two options should only be used, however, with the guidance and support of your stoma care nurse.

Q: *I have recently received a stoma and I wonder what I should do about exercise.*

I have never been very active and I do not want to join a gym. I have heard that Pilates and yoga are suitable for gentle exercise? Would this help to strengthen the muscles in my tummy area and stop a hernia?

A local support group has started chair yoga and I am wondering if this would help.

A: You do not say how long ago you had your stoma fashioned but if it is longer than three months ago then exercise is certainly a good idea. You can do many different types of exercise to suit you and the chair yoga is possibly a good starting point. I always recommend that you inform the instructor that you have had abdominal surgery; you don't need to go into specifics but by informing them they can assist you in the correct type of exercises and give options for slightly easier movements to start with. This would help to improve your abdominal strength whilst reducing the risk of a parastomal hernia forming. Good luck and enjoy.

Editor's note:

You may find it useful to read the **Colostomy Association's** new leaflet, **Active Ostomates**. Visit our website **www.colostomyassociation.org.uk**, click on information and scroll down to Literature and Factsheets to view or download a copy. Alternatively ring our head office **0118 939 1537** to obtain a printed copy.

If you have a general medical question or a query about stoma management:

E–mail:

editor@colostomyassociation.org.uk

or

Write to:

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

Your questions will be passed on to Julie Rust. Although Julie is not able to reply directly to you, her answers will be published in the next issue of *Tidings*.

Julie's answers to questions about issues such as leakage, rectal discharge, or managing hernias or retracted stomas etc. may not only help you, but may also provide advice and reassurance to others experiencing a similar problem.

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 **CA Ltd.** Return all required items to:
Colostomy Association, 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: **CA Ltd.**

Signature of self or carer: ____________________ Date: / /2016

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

Readers' writes

Rosemary Brierley

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 in or e-mail us today. The editorial team looks forward to hearing from you.

Dear Editor

I would like to say how much I appreciate your magazine. I am a comparative newcomer in this field having had an elective colostomy only two years ago. Unlike those readers, who will have had their ostomy for emergency health reason, I had a number of years to make that decision.

I am a widow, very active and in my 70s. Ever since I can remember I have always suffered from severe bouts of constipation and then during the past few years I suffered more and more from faecal incontinence with embarrassing consequences, and so my lifestyle became drastically curtailed. From being a very fit sportsperson, smallholder, world traveller and active grandmother, I found myself hardly able to leave the house.

I was referred to a number of specialists, had endless tests, biofeedback treatment, peripheral nerve evaluation and two bouts of surgery none of which made any improvement. So after five years of unsuccessful treatment I elected to have a stoma. A choice I have never regretted for one moment – I am now back in control – do not have constipation any more or the worry of incontinence. I am back to travelling, riding my horse and skiing as well as doing the normal things of everyday life without worry.

Even better, thanks to your magazine, I was introduced to the idea of colostomy irrigation six months ago. With help from the wonderful team of local stoma nurses I am now an enthusiastic irrigator. With my life back in my own hands I feel I can do anything.

Thank you all so much for producing such a great magazine and wonderful backup.

Yours sincerely
Helen Foster

Dear Editor

I have had an ileostomy for four years, and I'm very confident with my stoma, but find reassurance in having a travel certificate when going through airport security. I feel better being able to hand over my card, rather than trying to explain directly to a busy security officer.

This March, I was travelling to Cyprus from Manchester airport. The security officer insisted I put my travel certificate in the tray for scanning, even though I tried to explain I needed it if I was stopped for a body search. I wasn't stopped, but my luggage had to be checked as my ostomy bags were in the hand luggage. The officer searching my luggage was very good, and guessed it was medical equipment. However, if I had had my card in my hand rather than in the tray I would have been able to show him, rather than trying to explain in public, so I decided to write to the Department for Transport.

Although I have an ileostomy, I find the *Tidings* magazine very informative. Issue 41 prompted me to think about contacting yourselves to perhaps raise this issue. Before I had chance, I attended a local stoma event, where I met a volunteer on the **Colostomy Association** stand. She told me that there is a regular turnover of staff at Manchester airport but she would raise the problem for me.

Great, I thought, something might get done then, blow me, I had a reply from the Department for Transport, asking a couple of questions to establish some of the facts. I then received a letter apologising for my experience and stating: "Although we do not have specific advice for an ileostomy, the Civil Aviation Authority (CAA) website advises passengers with medical implants and prosthetic devices, whether fitted internally or as an external device, to take a letter from their GP explaining their condition for the benefit of the security officers at the airport which may help ease their passage through the security search point." It also states: "If possible, the letter should be shown to the security staff before you go through screening." The officer also stated they would: "forward these details to Manchester Airport so they can check that their

CONTINUED ON PAGE 50, COLUMN 1

Readers' writes

CONTINUED FROM PAGE 49, COLUMN 3

security officers are all aware of what should be done in these circumstances."

I was amazed that I got a response from the Department for Transport, not just a standard reply. Although I work for public services, I still feel that authorities don't listen to the individual but I was happily proved wrong. If anyone else has a similar experience, the contact details are Department for Transport, Great Minster House, 33 Horseferry Road, London SW1P 4DR Tel: 0300 330 3000.

A thank you to *Tidings* for having the article which prompted me to write the letter, the **Colostomy Association** for offering to speak to Manchester Airport Security and more importantly, the officer at Department for Transport, who took time to consider and act on my letter.

So, don't feel that as an individual there's nothing, you can do if things need changing. It's only the cost of a stamp or the time to send an email.

Happy Holidays
Karen Salisbury

Editor's Note: Following on from our visit to Manchester Airport back in 2010, a letter has been sent to their Head of Airport Security offering their team a training workshop, enclosing a travel certificate and seeking up–to–date security search information for inclusion in our Travel Advice booklet. A letter has also been sent to both the Department for Transport and the Civil Aviation Authority, thanking them for their support.

Do bear in mind that there are an estimated 120,000 ostomates in the UK and most of them never mention they have a stoma at the airport and are not challenged when going through security.

Dear Editor

When you book a flight with British Airways it pays to actually read the email flight confirmation you receive. There's a paragraph that starts:

Disability and mobility assistance

Please contact us if you have a disability so that we can give you the help you need. You can reserve your seat for free…

I made my booking and within 24 hours I had seats booked on four flights (easy loo access being a necessity!) and it didn't cost a penny. All it takes is an email on one of their contact forms.

Kudos to you BritAir!
Adrienne

Dear Editor

You were asking about a sport or hobby one did with a stoma. I have a stoma and a suprapubic catheter due to endometriosis, and I ride horses.

As long as I make sure my bag is not folded or crumpled and my catheter is down the front of my leg, not down the side where my saddle is, there is no problem. I wear jodhpurs hence the smoothing out of my bag.

I also want to thank you for the article, 'One Pouch instead of Two'. I had to decide whether I should have the wet colostomy, but your article made me think twice about it and I have decided against it.

Please accept my donation to say thank you for an excellent magazine.

Yours sincerely
AFD

Dear Editor

I am seven weeks post–op, living with a colostomy (Horrid Henry) and adjusting to a new way of life. I have received two issues of *Tidings* and find them very useful and informative.

I realise that I am not alone in what I am experiencing and these things happen to everybody and I am hoping to become a member of a support group, having found a couple of numbers in *Tidings*.

Regards
Janet

Dear Editor

I am an 83 year old gentleman who has had a stoma for ten years now. I also have a hernia. I have a suggestion which may be of help to fellow colostomates. I previously found that my trouser waist was cutting across where my stoma was formed, causing a painful soreness. I consulted my stoma care nurse who informed me that you can have high–waisted trousers made to measure, thus missing the stoma. When I made enquiries as to the cost of these trousers, I was told £200 a pair which I thought was rather expensive.

Then I thought why not purchase a pair of trousers off the peg a waist size larger and wear braces to support them. This keeps the waistband away from my stoma and it works perfectly. No more soreness.

I hope this will be of help to fellow colostomates.

All best wishes
RKD

Dear Editor

I have a problem caused by the waist band height of shorts and trousers. I have one pair of cargo pants and Primark sell shorts that measure 30cm from crutch to waist band and these work admirably. The others restrict the output of faeces by creating pancaking.

Do any of your readers have the same problem and know how to solve it?

David

*Editor's Note: The **Colostomy Association** have a clothing factsheet which lists manufactures of reasonably priced, off the peg, high–waisted trousers. Visit our website **www.colostomyassociation.org.uk**, click on information and scroll down to Literature and Factsheets to view or download a copy. Alternatively ring our head office **0118 939 1537** to obtain a printed copy. If any readers are aware of any other stockist of high–waisted trousers please let us know.*

Dear Editor

I do wish that contributors to *Tidings* would choose their words more carefully. To anyone anticipating or dealing with a stoma words like "terrifying" and "overwhelming" ('One pouch … instead of two': Issue 42) are not encouraging.

To go into hospital with a normal body and come out with a stoma – or two – is life changing, but not terrifying. My own experience, after four months of operations and procedures, was to give thanks and never ending appreciation that the dedicated Colostomy Team at The Royal Bournemouth Hospital had persevered – and succeeded – in giving me 'another bite at the cherry'.

Hello, my name is Bart

I am a stoma and I arrived on 24 December 2015 – so I am fairly new to this world

For two weeks my human did not want to know me – never mind clean me, or change my bag like our humans are supposed to do. I was so upset.

But gradually the kind stoma nurses introduced me to her and gently, but firmly, helped her to look after me and our friendship started to grow.

It was one of the junior doctors who said I should have a name as humans always just referred to me as he! For some unknown reason she called me Bart – you can guess what my human's seven year old granddaughter rhymed me with!

Our friendship has grown from strength to strength, but OK we still have our ups and downs.

My favourite trick is to keep leaking when she is trying to change my bag for a clean one. Oh boy does she get mad at me then. Another one is just after she has changed me. I let her sit down and relax and then I fill up again.

The other night at about 2am I leaked and my human said: "Never mind, Bart, it wasn't your fault, you couldn't help it." Now that is progress.

I think I will be with my human for about a year and then her consultant says he might reverse me, which doesn't sound very nice. Well not for me.

I met two lovely stomas and their humans while in hospital. Poppy and Squirty Bertie and we often exchange texts and phone calls via our humans. It is fun to hear that they have also been naughty and playing up.

When our humans are better we plan to meet up for coffee and a chat.

To all you new stomas out there – don't worry, at first your human will find it very strange having you come and live with them. Like mine it will take time for him/her to adjust to you, but you will soon build up a relationship and she will care for you and look after you.

I love my human

Sent in by Daphne, who tells us that "Bart will soon be going home." She will be having a stoma reversal as this issue of *Tidings* goes to press.

Don't forget our Recycling Appeal

Recycling Appeal is a multi-product technology appeal to raise funds for **Colostomy Association.**

Freepost envelopes are available or collections can be organised.

Simply visit:

http://www.recycle4charity.co.uk/Register/C60511

Readers' writes

One swiftly learns how to deal with a stoma plus the output from a permanent rectal abscess. Of more concern is putting up with the discomfort from a magnificent parastomal hernia. (How did those Victorian ladies put up with their corsets?) One learns to carry spares at all time – even to the local shops. My 'manbag' is now a necessary feature of life, but then ladies have been unable to do without handbags for years – so what's to worry!

At eighty–five years of age I still do most of the things that I did at sixty–five – and quite a few that I did at forty–five when I retired for the first time from the police force. We still holiday on the Continent by car, we still enjoy a social life with rather too much food and wine and we still enjoy our married life to the full; in that I am so lucky to have the love and support of my wife.

When anticipating or dealing with a stoma one has to be positive and appreciate how lucky we are to live in a country where such medical assistance is available. The poor people in Africa and other developing countries who have to use plastic bags, tin cans etc instead of custom made pouches, to contain their stoma output are the people to whom a stoma must be terrifying and perhaps overwhelming.

With best wishes
Yours sincerely
Roy Harvey

Dear Editor

In February 2008 I had an operation to form a permanent colostomy, after a previous two operations: the first a Hartmann's procedure in November 2005, the second to reverse it in November 2006. After six months I was in excruciating pain as a large abscess had formed and was causing a blockage. The colostomy was permanent but to be honest I didn't care what was done to alleviate the pain.

From 2005 to early 2015 I used to phone my delivery company for my supplies. I would get the prescription from my surgery and forward it to them on receipt of the goods. This went on without any problem until the EPS system was introduced. My supplies would no longer be delivered in the manner which had been the norm, and the supply of appliances became so erratic. I was recommended to change suppliers. Not a good move.

On 1 August, I telephoned an order through to my new supplier and received a text saying they had received this and the order would be out to me in a few days. By 10 August I had not heard from them so telephoned, to be told, yes, they had the order and had sent off a chase letter to my surgery asking them to supply the prescription. I could not understand this as I thought that EPS stood for Electronic Prescription Service and that everything was done over the wire. How wrong I was: on receipt of my telephone call they raise a letter and post it to the surgery and wait for the response.

After making at least 10 phone calls I resolved the problem. My delivery company received the prescription, but hey ho, they were out of stock of some of the items I required.

Is it possible that suppliers and doctor's surgeries do not understand how urgently some of these supplies are required? In future I will put my request into my local pharmacy and wait for them to obtain what I want. At least I know the pharmacist will call me to tell me how long the wait will be before delivery.

Sorry I am moaning but I would be interested to know if anyone else is having the same problems. Incidentally, I have been irrigating my colostomy since May 2008 and have been on many holidays to various parts of the world without any serious problems.

Yours
Carole Phipps

Editor's note: To be on the safe side, the Colostomy Association recommends that if ostomates request an order through a supply company they should do so when they still have three weeks supply in hand. More information about ordering supplies can be found in the factsheet

Please Note: 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

Moved by something you've read in this issue of *Tidings* magazine? Do you have an issue that needs addressing or an experience you'd like to share with our readers?

The **Colostomy Association** regularly receives correspondence from supporters across the UK who would like to share their thoughts, experiences and personal tips.

All letters and e–mails are considered by the editorial team who decide which will be published in *Tidings* magazine.

If you'd like to send a letter to be considered for inclusion on the Readers' Writes page please send an e–mail to:

editor@colostomyassociation.org.uk

or a letter to:

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

Please make sure you include your full name and address and telephone number so we can contact you. Additionally, please mention whether the **Colostomy Association** has permission to publish your letter and whether you would like us to use your full name or just your first name. In the interests of confidentiality, if you do not give us permission to use your name we will publish only your initials.

Forthcoming Events at Local Support groups

Stevenage Ostomistics is having yet another fantastic year.

We are still enjoying some brilliant speakers and going on outings. We play dominoes and/or Pétanque at a local pub once a month with a meal afterwards.

Still to come this year:

Thursford Christmas Spectacular in November

Our Christmas lunch at Hitchin Priory in December.

Last, but not least, our Open Day on *Saturday 26 November*
(see page 55 for details)

For 2017 we have the following planned so far:

Major Paul Whittle will be back with another of his illustrated "Travellers Tales"

Jo Mabbutt will give her talk entitled "The city of London Livery companies"

Another fun quiz by John Burlison

A river cruise with lunch in the Lee Valley Park

For more information contact:
Judy Colston: 01438 354 018
Alfred Levy: 01767 316 958

let's talk!
Nottingham QMC
Stoma Support Group

Come and join us and enjoy your time at our friendly, supportive group meetings.

19 November 2016
Sharing experiences of the recently introduced Nottingham Appliance Management Service (NAMS) centralised prescription service for stoma products.

17 December 2016
Travel tips and an illustrated talk by an ostomate on his trip around the Caribbean

21 January 2017
New Year Party
New and long–standing members welcome.

18 March 2017
Dr John Dornan – What happens when a doctor goes to War – the history of medicine and surgery

For more information contact:
Mike: 0115 808 1356
Rosemary: 0115 982 6691
www.facebook.com/StomaSupportGroup

Does your local support group have a special event during the first six months of 2017?

Our winter issue will go out early in the New Year so if you have:

- an interesting speaker attending your meeting;
- an outing you'd like local ostomates to know about; or
- any other special event.

send an e–mail to

editor@colostomyassociation.org.uk

or a letter to:

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

2006 – 2016

Celebrating 10 years of Helping and Supporting Ostomates

This year the Wessex Stoma Support Group reached its 10th year of helping and supporting ostomates from Wiltshire and its closest counties. The Group was born from an idea generated by Michael Slater and Michael Beck BEM in 2006 that people with any type of stoma could help to support each other in one support group. So, together with four friends all with a stoma, we held our inaugural meeting which set the group on its way to where we are today – with 76 members ranging from Newbury in Berkshire to Frome in Somerset, Lymington in Dorset and the whole of Wiltshire, meeting six times a year in Wilton, near Salisbury.

During the last ten years, the Group has spread the word that it is there for any ostomate who wants help by meeting with other ostomates on a regular basis. Year by year, we have improved our ways of communicating; it first started by simply handing out flyers and also working with the wonderful stoma care team at Salisbury District Hospital consisting of Sandie Bryan (Lead), Suzie Dukes and Michelle Boucher, reaching out to help patients who needed additional support.

Over the following two years, we wrote and produced the group's information booklet and in 2010 we received a grant to buy a laptop computer. Then followed our very successful website www.wessex–stoma.co.uk which, together with the computer, opened up a whole new level of communication: we could contact suppliers, support groups, national organisations and our own members by the miracle of e–mail. Following this, we started to produce our own newsletter, ably edited by Emma, our communications person.

All of this led us to where we are now. To keep our members interacting with one another we hold informal events including our annual BBQ, Christmas meal and the Pantomime at Salisbury's Playhouse theatre. Keeping ourselves going meant a lot of work and we started fundraising. We started with local jumble sales and have ended up holding, among other things, two big Craft Fairs a year (Easter and Christmas).

This allows us to fund things like days out to places like Swindon Railway Museum and visits to manufacturers such as Pelican Healthcare, Salts Healthcare and Fittleworth, as well as keeping our newsletter going and our meetings continuing to provide the highest quality of support for our members.

As well as raising our own funds, we are lucky enough to be supported by Pelican Healthcare, who are now our main sponsors. We are also benefitting from Tesco's community support scheme, who allow us the free use of a community room for group get–togethers on Saturday afternoons throughout the year as well as supplying the tea, coffee, biscuits and cakes and raffle prizes.

On Saturday 23 April 2016, we organised our 10th Anniversary Open Day, which consisted of an opening speech on 'the need for Support Groups' by Ken Edwards, our Chairman. It was then officially opened by Councillors Phil Mathews and Andrew Roberts the Mayors of Wilton and Salisbury respectively. There were four presentations during the day by Mr Michael Floyd – Clinical Fellow in Urology, Suzie Dukes (*right*) – Specialist Stoma Nurse, Debbie Stenning – Community Stoma Nurse for Salts Healthcare and finally Michael Slater – Secretary Wessex Stoma Support Group.

There were nine display tables from companies and the national organisations. A buffet lunch was provided free, along with morning and afternoon coffee breaks, a special Anniversary cake was baked and decorated by Mrs Lisa Haskell and donated to the group and cut by the two founders of the group Michael Beck BEM and Michael Slater and the day was completed with the grand raffle drawn by the Mayor of Wilton. It was a wonderful day to celebrate a wonderful first ten years. We hope to enjoy many more to come.

For more information about the Wessex Stoma Support Group, contact:

Michael Slater, Secretary

Tel 01722 741233

email **wessex.stoma@yahoo.co.uk**

colostomy association
Helping ostomates since 1967

give with confidence

Thank you for your support

Regular donation

Every donation makes a difference – your support can help change lives across the UK. With your help, thousands of adults and children living with a stoma will be able to receive invaluable support through the Colostomy Association.

Please fill in this form to make a Regular donation by Banker's Standing Order. 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 and postal code telephone number thank you

My Details: Title: Name: Surname:
Address:

Postcode:
Telephone (home): Mobile:
Email:

Regular donation: I wish to make a **regular contribution by Banker's Standing Order** to the **Colostomy Association** in support of the charity and its ongoing work. I have completed the **Banker's Standing Order Form below** ☐ (Please tick).

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:
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 cancel any previous standing order in favour of this beneficiary).
***Please leave one month's notice to ensure donation processes through banking system and**
state your donation amount in words:
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:** / / 2016

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 want to Gift Aid my donation and any donations I make in the future or have made in the past four years. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

Signature: **Date:** / / 2016

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

Registered Office: Enterprise House, 95 London Street, Reading RG1 4QA
Registered Charity No: 1113471

colostomy association

Helping ostomates since 1967

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Thank you for your support

Single donation

Every donation makes a difference – your support can help change lives across the UK. With your help, thousands of adults and children living with a stoma will be able to receive invaluable support through the Colostomy Association.

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.

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)

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

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 want to Gift Aid my donation and any donations I make in the future or have made in the past four years. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

Signature: **Date:** / / 2016

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

Registered Charity No: 1113471

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

National Support Organisations

Support organisations for people with stomas and other bowel and bladder diversions

IA The Ileostomy and Internal Pouch Support Group
www.iasupport.org
Telephone 0800 0184 724
e–mail info@iasupport.org

UA Urostomy Association
www.urostomyassociation.org.uk
Telephone 01889 563191
e–mail
secretary@urostomyassociation.org.uk

Mitrofanoff Support
www.mitrofanoffsupport.org.uk
Telephone 01202 674336
e–mail info@mitrofanoffsupport.org.uk

IOA International Ostomy Association
www.ostomyinternational.org

Junior Ostomy Support Helpline (JOSH)
via the **Colostomy Association** Helpline
0800 328 4257
e–mail cass@colostomyassociation.org.uk

Breakaway Foundation
www.breakawayfoundation.org.uk
Telephone 01283 240253
e–mail info@breakawayfoundation.org.uk

Support Organisations for associated medical conditions

Beating Bowel Cancer UK
www.beatingbowelcancer.org
Telephone 020 8973 0000

Bowel Cancer UK
www.bowelcanceruk.org.uk
Telephone 020 7940 1760
e–mail admin@bowelcanceruk.org.uk

Macmillan Cancer Support
www.macmillan.org.uk
Telephone 0808 808 00 00
Monday–Friday, 9am–8pm

Crohn's and Colitis UK
www.crohnsandcolitis.org.uk
Telephone 0300 222 5700
e–mail info@crohnsandcolitis.org.uk

The IBS Network
www.theibsnetwork.org
Telephone 0114 272 3253
e–mail info@theibsnetwork.org

Stoma Care Open Days

Attending a stoma care Open Day is an opportunity to find out about all the ostomy products and services available and also a chance to meet other ostomates.

Colostomy Association volunteers, who all have stomas themselves, attend stoma care Open Days all over the country whenever possible. Do come along, call at our stand and have a chat.

Here are some Open Days, taking place during the next few months:

Northern General & Royal Hallamshire Hospitals Open Day

Hillsborough Arena, Middlewood Road,
Sheffield S6 4HA
11 October 10am – 3pm
Colorectal Nursing Care Services 0114 271 4015

Shropshire B.O.T.s (Bums On Tums) Open Day

Memorial Hall, Smithfield Street,
Oswestry SY11 2EG
13 October 10am – 3pm
Irene Constable 01691 238 357

Whipps Cross University Hospital Open Day

Wanstead & Snaresbrook Cricket Club
Overton Drive
Wanstead E11 2LW
15 October 2016 1.30pm – 3.30pm
Stoma Care Team 020 8535 6563

Kettering General Hospital Open Day

Corn Market Hall, London Road
Kettering NN15 7QA
19 October 1pm – 4pm
Stoma Care Team: 01536 492 011

A regularly updated list of Open Days can be found on the **Colostomy Association** website. To find a forthcoming Open Day in your area visit **www.colostomyassociation.org.uk** Click on news and events and scroll down to Open Days.

Information about forthcoming Open Days in your area may be sent to you by the **Colostomy Association**. These invitations are sent to Head Office, where our volunteers stick an address label on the envelope. The company involved provides the stamps or pays the cost of postage and pays an administration cost which helps to boost **Colostomy Association** funds. Your personal details are never disclosed.

Queen Alexandra Hospital Open Day

Royal Marines Museum
Esplanade
Southsea PO4 9PX
20 October 2016 10am – 3pm
Stoma Care Team 023 9228 6679

Ashford Hospital Open Day

Education Centre, Ashford Hospital
London Road
Ashford
Middlesex TW15 3AA
26 October 2016 9.30am – 11.45am
Stoma Care Team 01932 722 636

Southend University Hospital Open Day

St Margaret's Church Hall
Lime Avenue
Leigh on Sea
Essex SS9 3PA
27 October 2016 10am – 3pm
Stoma Care Team 01702 385 509

Gloucestershire Royal Hospital Open Day

Churchdown Community Centre
Parton Road
Churchdown
Gloucestershire GL3 2JH
11 November 2016 11am – 2pm
Katie Lawrence 0300 422 6702

Ostomistics Support Group Open Day

Oval Community Centre
Stevenage
26 November 10.30am – 1pm
Judy Colston 01438 354 018

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

Channel Islands

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

England

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
High Wycombe Stoma Support Group
Wendy: 07717 335 884

Milton Keynes Stoma Association
Thia Cooper 01908 679 295 /
mksa.sec@gmail.com

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 /
0783 666 1102

Cheshire
Countess of Chester Hospital Stoma Support Group
Stoma Nurses 0124 436 6170

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

Stoma Support Group
Catherine McIntosh: 0147 753 5071

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 or email:
pgill82171@aol.com

Darlington Support Group
Sister Jacqui Atkinson: 01325 743005

Durham Stoma Support Group
Katie: 0191 3332184

Cornwall
Cornwall & Plymouth Bowel Cancer Support Group
Keith Anderson: 0182 225 8618,
cbcsginfo@gmail.com or website
www.cornwall-bowel-cancer-support-group.co

Cornwall Ostomy Support
Ken Jones: 01872 863 106 or
www.cornwallostomysupport.org.uk

Ostomist and Carers Support Group
Christine Davey: T: 016370 850 895
E: chris.davey28@gmail.com or Mandy
Rowe: 01726 832 642

Cumbria
Grange Cancer Support Drop in
Marie: 0153 953 3279

Derbyshire
Diverted Local Stoma Support Group
Diane Manning: 0128 354 1311

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

Mid Devon Ostomy Support Group
Janice: 07923975051 or
jdkelly234@gmail.com

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

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

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

East Midlands
Newhall Stoma Support Group
Diana Manning: 0128 354 1311 or
Helena: 0793 233 1850

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

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

STEPS
Jackie: 0126 845 1937 or email: stepsessex@gmail.com

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 0794 182 7393

Hampshire

Solent Ostomates Support Group (New Forest Branch)
Ron Lever 0238 089 3949 / rdlever@sky.com

Solent Ostomates Support Group (S.O.S.)
Carole Summer: 0752 770 7069

Southern Ostomy Group
Caroline or Karen on: 07756 819 291 southernostomygroup@hotmail.com

Wessex Urology Support Group
Adrian Kuczynzki: 07910 786 978

Herefordshire

Herefordshire Stoma Support Group
Carol Steele 0143 288 0656 or email: carolsteeleglo@gmail.com

Hertfordshire

Colonise
Anastasia 0172 776 0981

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

Isle of Man

IOM Bowel Cancer Patient and Carer Group
Heather Norman: 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 01983 559 326 or Cancer Clinical Nurse 01983 534 180

Kent

Ashford Stoma Support Group
Carole Hobbs: 0130 381 4014 or Margaret Webb 0123 362 8807

Atoms Support Group
Maria Culleton, SCN: 0122 776 9679 or 0782 799 7424

Dartford Ostomy Group Support (DOGS)
Tracey, John or Sue: 0794 897 4350 or dogs-uk@hotmail.com

Dover Stoma Friends Group Support
Julie Bell: 0777 134 5703 or Ros Marshall: 0130 482 2696 or June Golding (Organiser): 0130 482 2696

M.O.G.S (Medway Ostomy Group Support)
Helen Or Tracey: 0777 360 5534

Maidstone Stoma Support Group
Judy/Kirsty: 0162 222 4305

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

Sheppey Ostomy Group Support (SOGS)
Shelley 07714 734 194 / sogs-uk@hotmail.com

SWAN Stoma Support Group
Heather: 0771 144 5312

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

Lancashire

North Manchester and Bury Stoma Support Group
Julie Meadows (SCN) 0161 720 2815 or 0784 120 6910

Oldham Stoma Support
June Wilde: 0161 312 5538

Phoenix Bowel Cancer Support Group
Sandra and Nicola 01253 291919, www.phoenixgroupbvh.com or email: phoenixbvh@aol.com

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/Rachel: 0147 646 4822

Sutton Bridge and Long Sutton Ostomy Group
0140 635 1617

London

Bowel Cancer Newham
Scyana: 0208 553 5366 scyana@tiscali.co.uk

ESSence (Ealing Stoma Support Group)
Wendy Hetherington: 0771 733 5884

Homerton Hospital Bowel & Stoma Support Group
Angela Davy: 0208 510 5318 or 0208 510 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

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

Norfolk

Kings Lynn Ostomy Friendship Support Group
For more info please call 01553 775 698 / 01553 674 962 / 01553 768 271

STARS (STOma And Reconstructive Surgery social support group)
Sylvia Hughes 01263 733448 sylvia.ruth.hughes@gmail.com

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull: 0771 447 9320

Hexham Ostomy Group
Judith on 0796 792 7286

Northumberland Cancer Support
members@northumberlandcancer supportgroup.co.uk

Nottinghamshire

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

Nottingham QMC Stoma Support Group
Rosemary Brierley: 0115 982 6691

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

Oxfordshire

Oxfordshire Ostomy Fellowship
Pat Longworth: 0123 552 4163

Shropshire

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

Staffordshire

Outlook
Moira Hammond 0778 840 2195

Suffolk

East Suffolk Ostomy Group
Marion Fisher: 0147 331 1204

James Pagett Ostomy Support Group (Afternoon Meeting)
Vicki Blackwell on 01493 663363

James Pagett Ostomy Support Group (Evening Meeting)
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

Normandy Colostomy Support Group
Marina Harkins: 01483 233 126 or 07852 554 049

Stoma Support Group
Robin Young: 01428 723 255

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

Tyne & Wear

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

NHS Molineaux Centre
Gordon Weatherburn: 0191 234 1109

Royal Victoria Infirmary Support Group
Gordon Weatherburn: 0191 234 1109

Warwickshire

Warwickshire Stoma Support Group
nuneatonstoma@aol.com

West Midlands

Coventry Stoma Support
Martin: 0794 738 5643

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

Yorkshire

Acorn Ostomy Support Group
Michelle: 0758 069 3155 (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

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: 0798 956 5335 or Pete Rennard: 0793 951 8642 / 0148 279 3966 or Rosanna Grimsby: 0148 280 1575. www.hercosg.org.uk

Northern Ireland

Co. Antrim

Colostomy Association Volunteers Northern Ireland
Chris Wright: 0772 071 7771

Mater Hospital
Karen Boyd - Stoma Nurse: 0289 074 1211 Ext 2329

Royal Victoria Hospital - Belfast
Sarah Haughey/Audrey Steele: 0289 024 0503 Ext 3483

Co. Armagh

Craigavon Area Hospital
Mary Jo/Bernie: 0283 861 2721

Daisy Hill Hospital Support Group
Bernie Trainor: 0283 083 5000 Ext 2222

Co. Down

North Down Stoma Support Group
Adrian Ewing on 0785 074 1511

Ulster Hospital
Hazel/Martina: 0289 055 0498

Co. Fermanagh

Erne Hospital
To be confirmed

Londonderry

Causeway Support Group
Mary Kane: 0287 034 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

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: Morag Sinclair 0141 779 1322 or Jackie McChesney 01505 324 052

Moray

Moray Ostomates Support Group
Meggie 01343 552 449 / Kathleen 07789 684 285

Scottish Borders

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

West Lothian

GOSH (West Lothian)
Scott Pattison: 07502 163 644

Wales

Bridgend

Bridgend Ostomy Patients Support Group
Anita Brankley (Secretary) 0165 664 5602 or bridgend.ostomy@gmail.com

Carmarthenshire

Support Group
Iris Williams: Iris.Williams@wales.nhs.uk

Denbighshire

North Wales Ostomy Support Group
Debi Devine 0787 676 2503 / Hazel Duke 0797 681 7246 / Email: devinetherapies@btinternet.com

Flintshire

Bag For Life Stoma Support Group In.It.Together
Faye Jones 0785 275 0772

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 Suport Group
Colorectal Nurse Team on 0168 572 8205

Pembrokeshire

PSA (Pembrokeshire Stoma Association)
Roy Whitfield 0143 776 0701

Powys

The Bracken Trust Cancer Support Centre
Helen Davies: 01597 823646

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

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