SUMMER 2016 | Issue 42

colostomy association

Tidings

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Cover story

- Speaking out...

Inside

- Life aboard a narrow boat
- Going to a music festival
- Double–barrelled wet colostomy

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dear READERS

Our cover this time promotes Colostomy Day when our volunteers and supporters will be speaking out…or keeping quiet to make the public aware that well over 100,000 people in the UK live every day with a stoma. These days my colostomy causes few problems and I like to choose who I tell, so on Colostomy Day I will remain silent, but you may possibly spot me in some public place reading a copy of *Tidings*.

I would like, however, to send my sincere thanks to all of you who will be speaking out. Your openness and honesty will make it so much easier for us if we wish to tell others about our stoma. The more publicity it generates the more likely it will be that anyone who experiences problems with their stoma will be treated with understanding and respect, and the public will be less inclined to challenge us if we need to use an accessible toilet.

Thaila, who appears on our cover, will be speaking out. In the centre page story she says that she only writes about her stoma on Mondays on her blog 'Ostomonday' but she will be making an exception on Saturday 1st October.

Most people know what the word colostomy means; they may not, however, be familiar with stoma, ileostomy or urostomy. They are even less likely to have heard of a double barrelled wet stoma. Clinical Nurse Specialists, Jackie Tunnicliffe and Amanda Gunning, explain this very rare procedure and John describes what it is like to live with one, and how having this more challenging type of stoma didn't prevent him from flying to South Africa.

There are ostomates everywhere, sometimes in places you'd least expect. Margaret and her husband have lived on a narrow boat for the last 12 years, enjoying the leisurely life cruising Britain's inland waterways and canals. Paul recently attended a music festival and is pleased to report that the organisers are making provisions for people with disabilities at Glastonbury and accessible toilets are now on site.

You may have noticed a new name among our list of editorial team members. We are very pleased to welcome Philip Young who has kindly agreed to join the team. Philip has been a volunteer for the **Colostomy Association** since 2009 and attends as many stoma care Open Days as he can in and around Gloucestershire. We will be including Philip's story in the Real Lives section of the next issue of *Tidings*.

Finally I would like to say thank you to the trustees of the **Colostomy Association** for inviting me to become editor of *Tidings* again. The position is not completely new to me as I was editor from 2006 until 2008 and have remained a member of the editorial team ever since. *Tidings* has always been "very close to my heart" and I am happy to take on the role of editor in a voluntary capacity. Together with Sarah Squire, who I'm delighted to say has agreed to become assistant editor, I will do my best to produce an interesting and informative magazine.

I have to say that the strength of *Tidings* lies in the editorial team. We all work together discussing ideas for future issues, sourcing articles and considering your contributions. In the end, however, it is the letters and stories that you, our readers and supporters, send that give *Tidings* its human feel. So please do continue to send your contributions to your magazine.

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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Life aboard Amy Em

In 2004 former Colostomy Association volunteer, Margaret, and her husband realised their dream of spending their retirement living on their narrow boat, Amy Em, and cruising Britain's inland waterways and canals.

When we married in 1964, friends joked with my husband that he should always be sure to carry a good supply of pennies around with him; I had a reputation, even in those days, of needing to find a loo urgently! Within the first year of marriage I developed a rectal abscess and complications followed; several fistulas made life very unpleasant for a newly–wed. Eventually, after seeing more of hospitals than our own little home, a healing of sorts happened, but the heartache came when we were told it was very unlikely I would ever have children due to all the internal damage to my plumbing.

My faith as a Christian was sorely tried at this time, but I believed that with God all things were possible so my prayer was often rather selfish in those days. After some years, it was with great joy that I received the news that my depression was due to hormonal changes and a baby was expected, indeed I was four and a half months pregnant. Amanda, our eldest daughter, was born relatively normally three and a half months later, a tad light in weight but with an excellent set of lungs! She was nearly nine months old before I was completely healed and we were advised against having more children as I had severe internal damage. I often wondered afterwards why a Caesarean wasn't performed – somewhat uncommon in those days, perhaps.

There followed the usual ups and downs of parenthood and exactly two years later our second daughter, Dianna, was born, this time with no complications apart from the usual soreness of childbirth. We felt the gift of our girls completed our family, and for the next 22 years our life together moved on as normally as any other family.

Then I began to experience great pain and seemingly an inability to 'hold on'. Our GP sent me to a local consultant who, after nearly a year of poking and prodding and several episodes in hospital, felt I should be seen by a specialist consultant. I was referred to St Mark's Hospital in Northwick Park, Harrow. I remember the relief I felt that finally I had met a man who knew what was wrong, and how to treat me. In the meantime my husband had retired from the Sussex Police Force and we had bought a narrow boat; this was to fulfil our lifetime dream of cruising the inland rivers and canals.

St. Mark's almost became a second home to me as once again I was hospitalised regularly. Just before Christmas in 1996 my surgeon said I had Crohn's disease. I was shocked by this news as all I knew of Crohn's patients was that they were very thin whereas I had always been on the plump and healthy–looking side.

It took me some time to come to terms with this diagnosis. Finally in 1997 after three more procedures, my surgeon said he felt the only way forward was to give me a colostomy. Now into our lives came several people who either had one, or had nursed people with a bag and I was very grateful for their input at this time. One told me of the British Colostomy Association (BCA), as the **Colostomy Association** was called then, and after several calls to the office, I became well informed about what having a bag might mean. My family were all very supportive and a gem of a stoma nurse in Milton Keynes gave me courage to face surgery in the October of that year. The operation actually took place on our wedding anniversary!

I eventually made a good recovery and began to adjust to life with a bag. Oh yes, there were some blips, as I like to call them – the bags leaked, sore patches didn't heal well – but I began to realise how much more freedom I had in my life. Initially it took me nearly half an hour to 'sort myself out', now it's down to minutes. I discovered that Hollister closed bags suited me, and have used them ever since.

As I developed a parastomal hernia two more major operations have since followed the initial one. Unfortunately, the hernia is still with me and has caused me to have a few blockages over the years. I now know certain foods like raw apples, beetroot and sweetcorn cause problems, so I avoid them if possible.

After my initial operation I had hoped that I could have a reversal but this wasn't possible as by then my sphincter muscles had completely broken down. At this time I trained as a volunteer with BCA and during the course of one of the training sessions, I realised that I was in fact grieving for the loss of my body part. Being a bag lady was permanent, and I needed to adjust to this. I enjoyed working on the Helpline, just sharing with others the things that had helped me on my journey to what is now a normal life.

We finally realised our dream of cruising on our 15m (50ft) narrow boat, Amy Em, and over the last 23 years have covered most of the connected inland waterways. Life on board is gentle and very laid back. Friends who cruise with us just for a day say they feel so refreshed by the slow pace of life, and the wonderful scenery. For the past 12 years we have rented out our house and moved permanently on board. As my husband is physically fitter than me, he has all the rope hauling hard work to do. I get to be Captain and steer the boat.

We are often asked what it's like living on a boat. Well, life is what you make it… wherever you live. The most frequent question is: "Is it cold in the winter time?" No, water is a great insulator so we don't suffer from cold feet or chilblains. In the centre of the boat we have a solid fuel stove on which we use smokeless fuel, usually bought from a coal boat trader, and burn everything burnable including our rubbish. On top of the stove we have an eco fan which wafts the air around, so warm air reaches the furthest end of the cabin, which is our bedroom.

In the past eight years during the winter months we have had a permanent mooring in a marina, so our luxury has been electricity. We could plug in and use a normal kettle, toaster and satellite TV. When we're out on the cut (canal) we use calor gas for cooking. Electricity comes from a bank of 12 volt batteries, similar to a car battery system. These are boosted by a large solar panel on the roof. When the boat's engine is running it heats up our calorifier which is like an immersion heater.

We carry 250 gallons in our cold water tank and one winter when we were stuck fast in the ice we proved that if we are careful this can last us for three weeks! Water points and rubbish and sanitation disposal points are placed fairly conveniently along the canal side. Our loo is a modern 'bucket chuck it' and a shower completes our wet room.

Friends who know I have a colostomy have asked how I get my supplies and how I dispose of used bags. Respond have always delivered my supplies wherever I am with no problem; they are used to having different delivery addresses for me; suitable pick up places like a friend's home or a marina en route. Most of our canal network has dog waste bins strategically placed along the towpaths, as do most towns and parks, so I use them. However, when we are out in the open countryside and well away from other boats or houses, then onto our solid fuel fire they go; two bags will almost boil a kettle!

Due to our wonderful National Health Service we have never been let down by either a local surgery, or even the emergency services when needed. When I need to be in a certain hospital I either take a train or the National coach service; this pretty much covers most of the country, so transport has not been a problem. Generally we have found that boat people help one another; there's always someone with a car to help out in an emergency.

In recent years our daughters have been concerned by our nomadic way of life and think that at our great age (we're in our early 70s) we should put down some roots and stop escaping into the countryside. As a concession to this, we have had a 'granny annex' built onto one of their homes and have spent our first winter on land. In April we once again moved onto Amy Em and we now hope to cruise for the next five months taking in a two month trip on the Thames.

Having a bag is the best thing for me. I call my colostomy Mount Vesuvius, as in its early infancy it had a habit of making rude noises, especially in a quiet place. My stoma nurse said if that happens, just stare at the nearest old person…Well, now I am one of the older ones, so I just shrug and let it happen, although a well–placed finger can sometimes defer its misbehaviour.

What I would say is: "Be brave, there is life after stoma surgery." It wasn't the end of the world for me but a wonderful beginning, and there is so much more that I can now achieve.

Margaret Wright

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One pouch… instead of Two

The Double Barrelled Wet Colostomy

Jackie Tunnicliffe, Hollister Clinical Nurse Specialist, The Royal Marsden Hospital
and **Amanda Gunning**, Clinical Nurse Manager, Hollister Ltd.

A diagnosis of cancer and the knowledge that you will need a stoma for the rest of your life is terrifying for anyone, but being told that you need two stomas must be overwhelming.

There is, however, an alternative surgical technique, requiring only one instead of two stomas, which is available to a select group of patients with a unique set of circumstances. This technique is called a *double barrelled wet colostomy*. The operation involves a total pelvic exenteration.

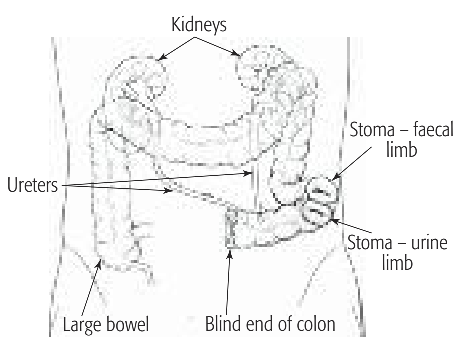
A total pelvic exenteration is a radical procedure which is undertaken when cancers are locally advanced. This means that they not only involve one organ but have also invaded another or multiple structures in the pelvic cavity. The bladder, rectum and anus are involved and this requires removal of these organs resulting in diversion of both urine and faeces. It may also involve removal of (in females) the uterus, ovaries and vagina, and (in males) the prostate.

Usually this surgery would leave a patient with two separate stomas, one for faeces (colostomy) and one for urine (urostomy). The Double Barrelled Wet Colostomy (DBWC) as defined by Carter et al in 1989 is an alternative.

This procedure is not an option for everyone who is due to undergo a total pelvic exenteration. The decision making process requires intensive evaluation of the cancer itself, a comprehensive assessment of surgical suitability, provision of information and intensive support. It is a relatively new procedure in the United Kingdom, and it is not undertaken lightly.

What is a DBWC

A DWBC is essentially formed as a loop sigmoid colostomy with the upper limb of the loop passing a semi formed stool. The lower limb is for urine. The ureters (tubes which normally convey urine from the kidneys to the bladder) are implanted into the lower limb (the end of which has been closed off when the rectum was removed). This allows the patient to wear just one pouch, which collects both faeces and urine.



What is involved?

After a cancer diagnosis has been confirmed from a biopsy and a complete set of scans including a CT, MRI and PET scan, the patient's case will be discussed at a multi–disciplinary meeting where a plan of treatment will be formulated. The lead surgeon, who deals with the original site of the cancer, will review the patient in clinic and then they will also be seen on separate occasions by all involved in the surgery including a urologist, plastic surgeon and stoma care nurse specialist and either a gynaecologist or colorectal surgeon. A pre–assessment appointment is arranged along with a cardio–pulmonary exercise test. This is necessary to assess fitness for the operation which can take in the region of 12 hours.

Advantages

The main and primary advantage to the patient is that they will only have one stoma. A recent quality of life survey of all the patients (23 at the time) demonstrated that this was the overriding benefit. Another advantage is that muscle from the stoma site is available for a skin flap, which can be stitched into the site of the old rectum to prevent this area becoming tight and painful.

Disadvantages

Patients with a DWBC require a pouch which will accommodate both urine and semi–formed stool. The current pouches on the market are not designed for this type of output. An alternative is to carry out colostomy irrigation of the faecal limb (see pages 22–25 for more information on irrigation) and to manage the urinary output with urostomy appliances.

Another concern is the odour as the combination of urine and faeces can be offensive. However, this is only a problem when emptying the pouch or night–bag.

Recovery

Most patients are in hospital for a minimum of three weeks. Recovery whilst at home is very much at an individual pace. Most people find that the average is about six months but part of this recovery process is in coming to terms with having a stoma.

Routine Care and complications of stoma formation

Care of the double barrelled wet colostomy is the same as with a separate urostomy and colostomy. Ostomates are still at risk of urine infections, pancaking, hernias and leakage and as always the best option to solve these problems is through your local stoma care nurse or the relevant associations.

Conclusion

The double barrelled wet colostomy is an option for patients with a unique set of circumstances. Patients need to be aware that this is a relatively new procedure with little peer support but is a viable alternative to two stomas.The majority of the patients who have had a double barrelled wet colostomy carried out stated in the quality of life study that they prefered having one rather than two stomas. ■

My Life with a Wet Stoma

On 5 September 2014 I had a major operation to remove a fairly large rectal tumour, together with other organs, and as a result I have a stoma. Not the usual type of stoma; mine is a double barrelled wet stoma which has an outlet for faeces and a smaller one for urine. At the time I think I was only the 10th patient to have this type of surgery at the Churchill Hospital in Oxford, and there were only a few carried out at other specialist centres in the UK.

None of the existing pouches were specifically designed for my condition. However, with the tremendous help I received from the stoma nurses in both the Churchill Hospital and the Great Western Hospital in Swindon, I have overcome these problems and have gained full confidence.

In September 2012 I noticed that I was having slightly more visits to the toilet and a tendency towards diarrhoea although no other difficulties. Following a visit to my GP it was arranged that I should have a fast track barium enema, which showed no significant abnormalities.

Assuming that everything was alright and feeling extremely well in other respects I continued living normally until November 2013 when I noticed a small amount of bleeding from the rectum when going to the toilet. My GP immediately referred me to a specialist for an examination which took place on 12 December. Then just before Christmas I had a colonoscopy which confirmed a malignant rectal tumour.

My next appointment was on 10 January 2014 with an oncology consultant, a lady who was extremely encouraging and helpful. She explained that chemotherapy should be commenced as soon as possible and that there was every chance that this would shrink the tumour sufficiently for an operation to be undertaken. After a further CT scan it was discovered that I had a small metastasis (secondary) in my left lung, which it was thought would also shrink with the chemotherapy, and could be operated on separately. She also told me that they were no longer using barium enemas to diagnose bowel cancer because they were unreliable! They preferred to rely on colonoscopies instead. I passed this information on to my GP who thanked me for this as it had not filtered through to him.

These were worrying days as one might imagine and I am so very grateful to my wife for all her support and encouragement throughout my long journey with this disease, particularly as she had undergone a triple heart bypass operation a year earlier.

There followed six months of chemotherapy which I found most unpleasant, but obviously very necessary. During this time my consultant was making contact with various specialists at the Churchill Hospital, Oxford, who she felt might be willing and able to carry out the necessary operation. Over this period I lost two and a half stone in weight.

Towards the end of my chemo there were further CT and MRI scans followed by meetings between the specialist surgeons to discuss the chances of success with this operation. Fortunately they were able to obtain the support of the Royal Marsden Hospital for the go–ahead.

On 5 September 2014 I had a seven and a half hour operation to remove my rectum, anus, bladder, prostate and lower bowel, and to have a plastic surgery repair. Because of this I had to have a wet stoma which is a single stoma which has an outlet for faeces (colostomy) and a smaller one for urine (urostomy), and requires just one bag.

The treatment I received on the NHS in the Churchill Hospital from all the staff on the surgical team right down to the ward support staff and particularly the nurses was absolutely magnificent. I had to be taught how to use and change my stoma bag and the stoma nurses were all so patient and helpful. Whilst nearing the end of my hospital stay my surgeon confirmed to me that all the margins were clear and there was no sign of any cancer left in that area. There had been comparatively few wet stoma operations when I had mine; I was number 10 at the Churchill Hospital, Oxford, and there had been several others in the North of England and some in the London area. I was warned that there was a slight risk of infection due to the close proximity of the two outlets in the stoma, and I did have urinary sepsis in my second week in hospital. This was rapidly dealt with using antibiotics and I was advised that the secret is to keep drinking plenty of liquids.

After leaving hospital I started having trouble with my stoma bags leaking; you can imagine the stress and trouble when this occurs either in bed at night or when away from home, and the difficulty in dealing with these. Our washing machine was working overtime! The number of times the stoma nurses and I tried different designs of bags seemed endless and yet no satisfactory improvement could be found. One might imagine the stress and strain our marriage was going through at this time, apart from the other difficulties. About three months after my operation I developed a hernia near the stoma from trying to lift heavy items, and this did not help the bag situation very much either.

Then my stoma nurse from the Great Western Hospital in Swindon suggested a 60mm two–piece stoma bag which has a high flow output tap to cope with a wet stoma. This was the answer to our prayers and the pathway to a new life. We could go on holidays, stay in hotels or stay with friends, and have our confidence back. My fingers have more or less stayed crossed ever since, and so far we have had no more troubles. I think that most of my problems with the stoma bags leaking stem from the fact that I have a wet stoma, and all the available bags are made for either a colostomy or a urostomy, but not both. The main reason for this is that there are so few of us who have had this particular operation.

When in hospital immediately after my operation, I used a urostomy night–bag and it was suggested I continue to use this when sleeping. A tube fits tightly over the end of my stoma bag drain tube and leads to the larger–capacity night–bag which sits on the floor beside the bed. This means that I can avoid having to visit the toilet right through the night, and can then deal with the not completely full night–bag in the morning.


Zebras at the Addo Game Park, near where John and his wife stayed at Port Elizabeth, 750 km North East of Cape Town, South Africa

Another helpful piece of advice I received was to consider irrigation. Now this is particularly helpful for people with just a colostomy, but surprisingly advantageous for people like me, as the combined faeces and urine in the same bag cause a number of problems, in particular odour. There have been helpful articles in *Tidings* magazine and there is an excellent DVD on the subject of irrigation available from the **Colostomy Association**. With the help of these and the supportive advice from my stoma nurses and my surgeon, I decided to commence irrigating some 10 months ago and continue to do this every other day.

In February 2015, it was necessary for me to have the small metastasis in my left lung removed and so I went to the Royal Brompton Hospital in London for this. All went well I am glad to say. I also had another minor operation on my right shoulder. In both cases I took a urostomy night–bag into the operating theatre, and I can assure fellow urostomates that this does not cause any problems as long as this fact is mentioned to the appropriate staff before the operation takes place.

A year after my operation I had another CT scan and saw my surgeon in clinic in November 2015. He was able to tell me that everything was all clear – no signs of disease – and he does not need to see me for 12 months. Naturally this was the best news I could have been given.

This gave us the confidence to travel to South Africa earlier this year. You might well ask how I got on with my stoma when away from home and particularly on a long flight. We were lucky to be staying with friends so we had our own bedroom and en suite bathroom, which made managing my stoma bag, night–bag and irrigation fairly straightforward.

On the flight out and back (11 hours 30 mins each way, flying through the night) the situation needed a little more concentration. Even though we were in Club class and had more room, it was not possible to use a night–bag for obvious reasons, so my wife and I had to make sure I was able to visit the toilet every two hours or so in order to avoid the stoma bag getting too full. To fail in this discipline would, you might imagine, be somewhat catastrophic! Fortunately due to excellent teamwork we avoided any problems.

I feel extremely fortunate to have received such wonderful treatment and advice throughout my rectal cancer experiences, and I felt obliged to write to the CEO of the Oxford Hospitals Trust to praise all the surgical and nursing staff for their skill, professionalism, hard work and dedication to duty. I had a very nice letter back from him and he passed my comments down to all relevant departments.

John

There appears to be an increasing number of double–barrelled wet stomas created for people who require both a colostomy and a urostomy.

If you have this type of stoma, please write in and share your experience of what works for you. John has suggested the possibility of starting up a wet stoma support group. If you are interested in being involved, contact the **Colostomy Association** Head Office.

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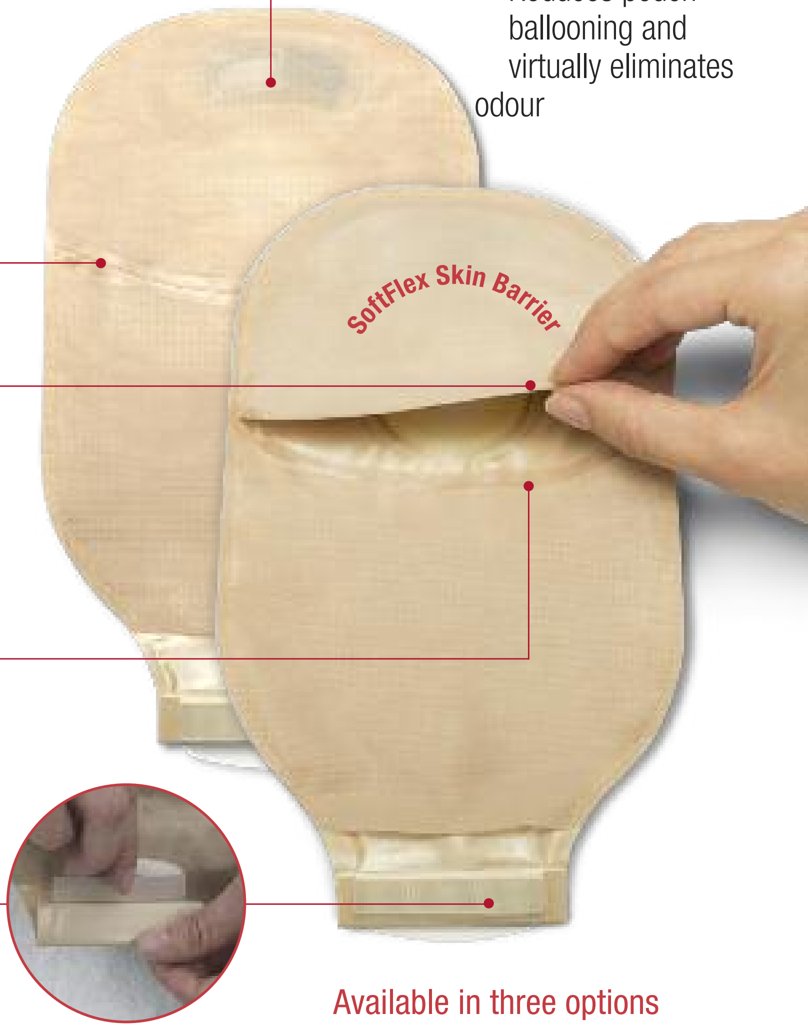

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From One Ostomate to Another

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

In the last issue of *Tidings* we included questions from ostomates about gliding, cycling and skiing together with answers from **Colostomy Association** volunteers, who participate in these sports. This prompted three of our readers to write to *Tidings* to tell us about their experiences.

Gliding

I have had two stomas (colostomy and urostomy) for 30 years. I enjoy regular flights in light aircraft at an altitude up to 7,000 feet and have never experienced any problems whatsoever.

My condition has never prevented me from enjoying any of my chosen activities, which are diverse and extensive. The list is endless, so I will not bore readers with it. In fact, having a stoma can be an advantage in some instances!

For anyone taking up gliding the main concern should be avoiding a mid–air collision, as gliders are difficult to spot in the sky. (I wonder why they are not painted bright orange!?)

Don't let your stoma stop you doing anything; it has never stopped me!

Enjoy flying and enjoy life,

Jayne

Do you have an experience you'd like to share with other ostomates, perhaps a sport, hobby or other activity you were unsure whether you would be able to continue once you had a stoma?

Or maybe you have a question about coping with a stoma in particular situations or hints and tips you'd like to pass on

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or

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Reading RG1 4QA

Cycling

Like A.P. I find the Rido2 saddle works very well after an APeR (an operation which includes the removal of the rectum and anus). My operation was done in the July of 2014, and, yes, it takes some time to get the confidence to actually try to sit on a saddle again! For me it took just over a year. I have now been on a couple of bike rides – one 11 miles and the second 20 miles on my Rido2 saddle, on a mountain bike. There were no ill effects/sore feelings, and the only aching was from using muscles unaccustomed to pedalling. Prior to this, I have built up my own fitness by walking as much as I can.

The biggest issue I have is with pancaking, and need to resolve this while wearing tighter cycling clothing. I intend to try wearing a support belt with a plastic shield inside.

Hope this information helps your reader

J.M.

Further to getting back on a bicycle after perineal surgery, a cycle shop assistant once pointed out that 'ladies' saddles are a quite different shape to 'mens' saddles. By design, 'ladies' saddles are a bit wider and support the rider's bottom either side of the centreline and have a lower area in the middle of the saddle to avoid unnecessary pressure on female anatomy. From personal experience I agree that this different shape makes 'ladies' saddles a good choice for either gender after perineal surgery.

Best regards

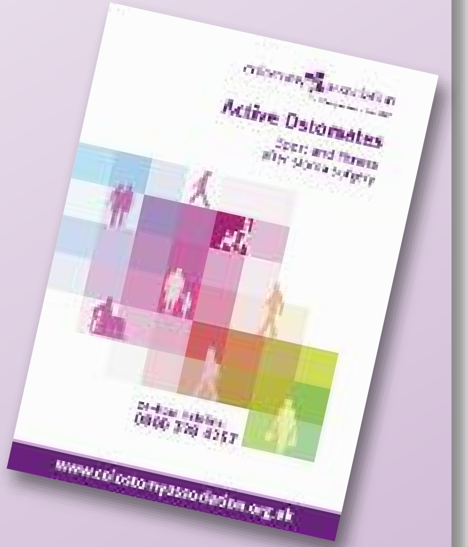
A.D.

Skiing

I had my stoma operation due to rectal cancer in July 2014 and have a permanent colostomy. Since then I have been building up my strength by walking as much as possible. I wanted to let your reader know that I have just returned from five days skiing so YES you can ski with a stoma.

The stoma itself had no impact at all on my skiing and the walking and fitness exercises I have done meant that there was no problem at all in terms of core strength. The biggest issue is aching legs from unaccustomed exercise of skiing!

Are you looking for ways to stay fit?



The Sport and Fitness after Stoma Surgery booklet contains information on simple exercises you can do at home as well as information on a range of sporting activities from swimming to yoga.

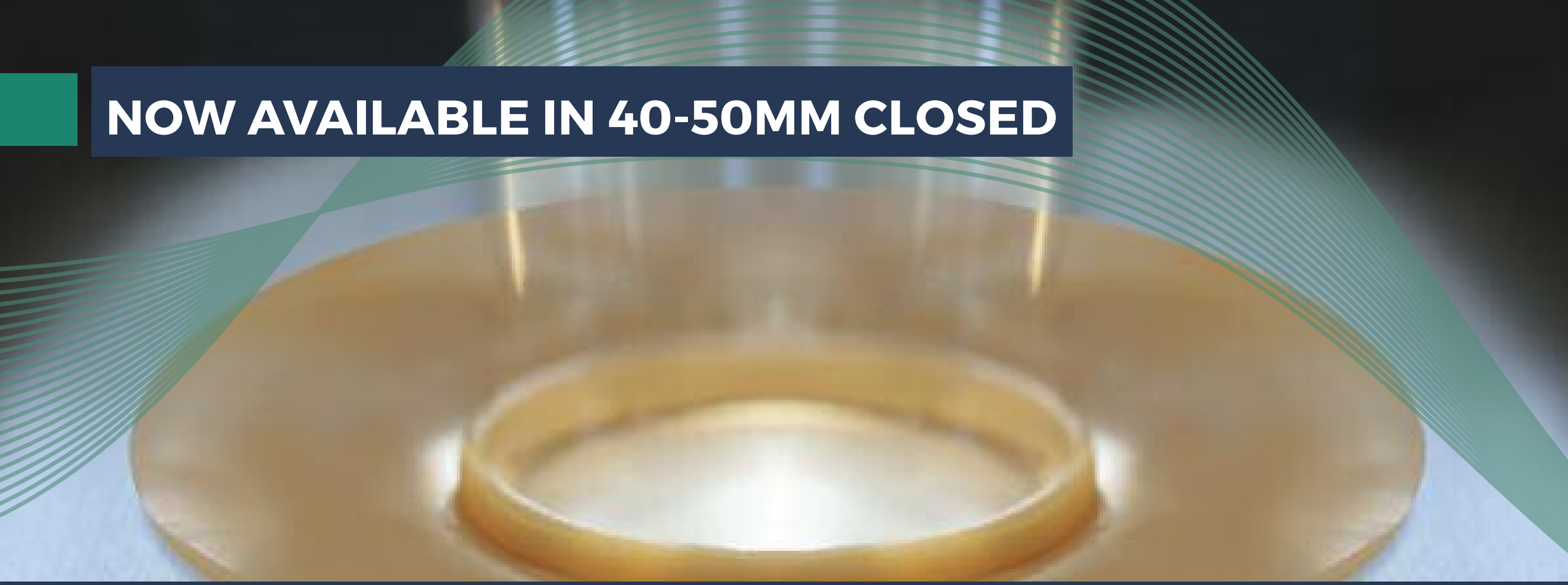
This booklet can be downloaded from the **Colostomy Association** website or a printed copy can be obtained by contacting head office.

The exceedingly good news from my point of view is that ski clothes can be adjusted to cover the stoma loosely so as to avoid pancaking. The arrangement that worked the best was just to have my ski salopettes done up very loosely round my middle. I did find that on one occasion when wearing a belt the movement of my body nearly pulled the bag off.

I did fall down a couple of times and just rolled over – no stoma issues here either. The other concern I had was sitting on the chair lifts. This also worked OK – even button lifts, where I put my ski sticks across the button seat as an extra support.

I think the biggest thing is to listen to your body, not push too hard at first, and build up through the time you have. After all, as someone said, it is meant to be a bit of fun!

A.D.



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PRODUCT CODE	DESCRIPTION	POUCH SIZE	STOMA SIZE	COLOUR	FILTER	QUANTITY
413509	Closed Split Cover with Filter	Standard	20-30mm	Opaque	x	30
413510	Closed Split Cover with Filter	Standard	30-40mm	Opaque	x	30
413511	Closed Split Cover with Filter	Standard	40-50mm	Opaque	x	30
413521	Drainable Split Cover with Filter	Standard	20-30mm	Opaque	x	10
413515	Drainable Clear with Filter	Standard	20-30mm	Clear	x	10
413522	Drainable Split Cover with Filter	Standard	30-40mm	Opaque	x	10
413516	Drainable Clear with Filter	Standard	30-40mm	Clear	x	10

Call **0800 834 822** to get your free sample or for more information.

References 1. Clinical Summary: Osmose Study, Multinational Evaluation of the Peristomal Condition in New Ostomates Using Mouldable Skin Barriers. Data on file. ConvaTec Inc. AP-016077-GB

Don't be afraid to ask

I am a woman in the afternoon–tea of her life – forget twilights and sunsets – and I am married to Robert, have one grown–up daughter and a grandson. I qualified as a teacher but spent most of my career working in male prisons, a very interesting job, I must add.

Around the turn of the century I became aware of some rectal bleeding, and when I mentioned it to my mum she said that she had it too, but not to worry as it was a "family thing" whatever that meant. So the coward in me told me that that was alright then. Leave it alone and it will go away. Only it didn't. I began to notice it more and more. It was weird, it didn't get on my clothes or anything, it was just there…on the tissue…in the toilet. I went to the doctor and was told quite cheerfully that it was "nothing to worry about", it was a common problem and suppositories would solve it. I went home relieved and happy. He was a doctor who knew all about these things and I was probably wasting his time.

This went on for the next six years. I saw a few different doctors who told me lots of wonderful things: it is piles and IBS (Irritable Bowel Syndrome) – the usual misdiagnosis – possibly diverticulitis, but not to worry, it will probably clear up on its own, piles again but very high up, little polyps, don't worry, lots of people get them, and, get this one, "wear and tear"! I asked what was meant by that as I don't ride horses or own a bike, only for it to be hastily amended to the old chestnut, "my age"! In my sixties what did I expect? By now I was worried, seriously worried. The blood was present every time I went to the loo and I was having short, urgent bouts of diarrhoea for no reason. I simply did not know what to do next. I had not been examined nor offered any follow up and if you don't know what is available, you don't ask.

I was saved by the home screening test. Lucky for me, I lived in a trial area; this was the very start of bowel cancer awareness and I firmly believe that it saved my life. I included a note about the rectal bleeding in with my test and a few days later received another one, which I did and soon I had an appointment with the colorectal clinic at Torbay Hospital. I was quite prepared for the result, I had known something was not right, so it was with great relief that I now had a name for my problem and someone who REALLY knew what he was doing was at last going to deal with it.

Things didn't go according to plan though. My consultant, the amazing Mr. Pullen, created an internal pouch first, hoping to spare me from having a stoma but it sort of broke down so one week later, feeling beyond poorly, I was back on the operating table. My first sight of my stoma came as a shock as my lovely nurse, Nita, hadn't been able to prepare me, due to me being so ill and I remember vaguely wondering how I was going to wear clothes again.

But I was alive! Mr Pullen had removed the tumour and I did not care one bit that I had a stoma. The choice between a bag or a box was a no–brainer. I won't bore you with that long road back to a normal life. Robert and I did a lot of talking and we decided to meet this situation head on, learn everything we could about it and deal with the ups and the downs. He did lots of research on the Internet. The learning curve was in place; we went to open days and tried various products.

Irrigation followed, though it is not a total success for me, Nita reckons I have a very sensitive colon so I often still need to do some emptying during the day, therefore a drainable pouch is a must. I could not imagine life without those little tissues for removing the build–up of glue that you sometimes get. Boomerangs, banana strips, or whatever you call them, are an extra security thing, same as those black Diamonds that turn your output into "caviar" thus preventing seepage which I do get via a shallow dip on one side.

We are all different which is why trial and error are so important. Never be afraid to ask for advice however trivial the problem may seem. My first granuloma terrified me. I thought the cancer had returned and that was it! *Tidings* put me right on that one. The magazine has answered many queries over the years.

I take great care of my "outside toilet" and often wonder if I would still be annoying GPs trying to find answers or…worse. I did feel a bit scared when Mr Pullen declared me fit to be released back into the wild, but I keep in touch with the brilliant stoma nurses. I know that they are there if I need them and I will always have a deep respect and admiration for the very un–glamorous job that they do.

Lastly…a huge thank you to *Tidings* and the **Colostomy Association** for giving me the chance to tell my tale and hopefully inspire others not to be afraid to…ask.

Donna Ashbrook

NEW

Confidence® Natural Advance

Confidence® Natural Advance now sticks faster, stronger and longer.

The 1-piece range now features wafers that are 30% stickier, which means improved security and less chance of there being leaks.

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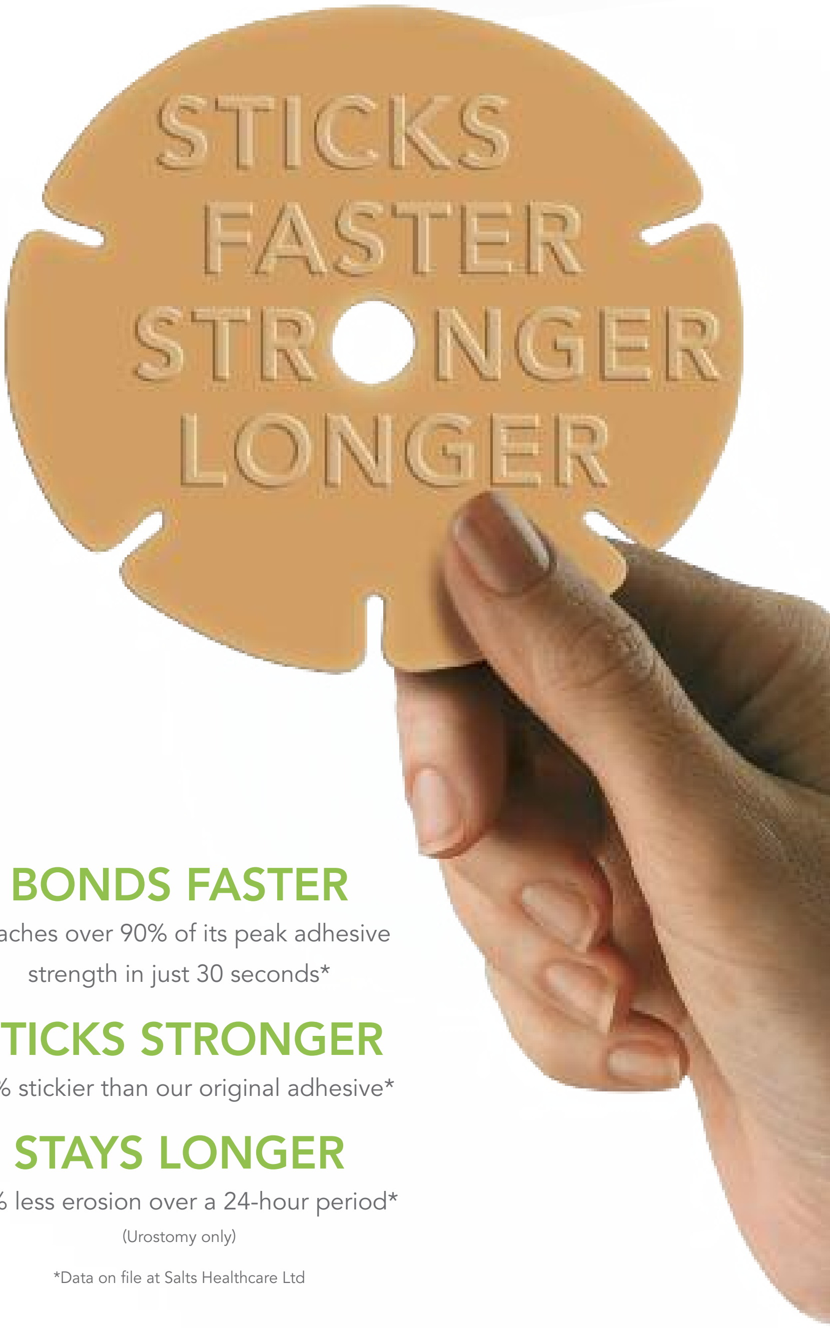

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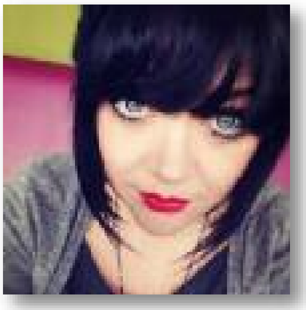
We need YOU! Fundraising is an immensely **important source of income** for the **Colostomy Association** as we rely heavily on donations. Help us continue to provide **support to ostomates and their families 24 hours a day, 365 days a year.**

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

Fundraising Focus

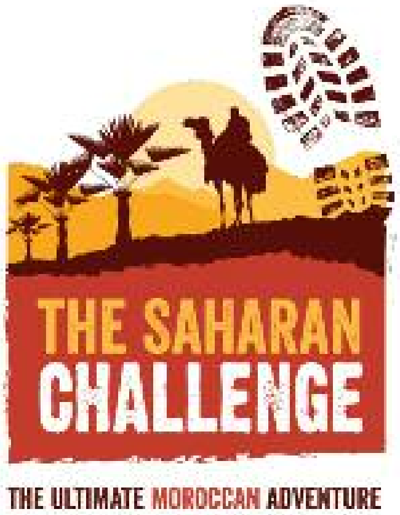
The early morning sunshine and the late evenings of summer seem to have had an inspirational effect on many supporters, their friends and family, as we have seen a large number of people sign up to take part in a wide variety of events to raise funds for the Colostomy Association. Once again we are grateful to all of them and to everyone who has taken the time to support their efforts.



Loz's Saharan Trek

Six years ago someone very close to Loz Tronic was suddenly taken seriously ill. After weeks of relying on life support, they thankfully recovered, but then had to make the life–altering adaptation of living with a stoma.

Loz spoke of what an extremely difficult thing their stoma was to cope with, but the challenge was tackled with bravery and pragmatism. Loz also mentioned that without the support of the **Colostomy Association** the journey would no doubt have been even harder for that person than it had already been. Loz described how vital our services are for colostomates and their families, both physically and emotionally.



After looking for something challenging to take on to help raise funds for the **Colostomy Association**, Loz came across the Saharan challenge.

The Saharan Challenge is a gruelling 52–mile organised endurance trek across Morocco, spanning two days in October and ending on the edge of the desert dunes.

Loz has already begun training which includes weekly cardio classes and regular walks, and in May Loz will be entering the second leg approximately 43.5km of the London2Brighton Challenge. Training will then intensify as the months close in. If you'd like to support Loz on her Trek you can do so through her Just Giving page at **www.justgiving.com/loz-tronic2**

20 Miles to go…

Avid swimmer Wendy Rogers has pledged to swim 32km in aid of the **Colostomy Association**. The swimathon is taking place over a 12 week period between April and July, with Wendy already well on the way to reaching her target. Following publicity on social media Wendy's efforts have also inspired her friend Pauline Morgan.

…and 21 Miles for Pauline!

Pauline Morgan has decided to tackle the English Channel from the comfort of her local swimming pool!

Pauline has had a stoma since 2008. In 2010 she discovered the **Colostomy Association** when she was given a copy of *Tidings*, and in 2012 Pauline joined the closed CA Facebook group. Pauline explains why she decided to take on the sponsored swim:

> "The **Colostomy Association** has helped me so much, will you now help me to say 'Thank You' by sponsoring me in my swim? I will try to swim 21 miles, the width of the English Channel when the tide is out. I started on the 1st April, April Fools Day, or should that have been Old Fools Day in my case? And I hope to finish by the 1 July (around the time this edition of *Tidings* will arrive). I think that this is a realistic time line but it will also be a challenge for me, so please will you support me."

You can support Pauline through her Just Giving page at **www.justgiving.com/mrsmog**

Purple Power!

The Color Run is the original, largest and most unique 5km run in the world, celebrating healthiness, happiness, friendship and having the time of your life. Sisters Natalie Doak and Debbie McShane will be entering the Glasgow leg on 17 July this year to raise funds for the **Colostomy Association** and to celebrate their mum, Susan, who's had a stoma since 2012. You can support Natalie and Debbie on their Just Giving page **www.justgiving.com/Natalie-Doak**

Garry gets on his bike

Garry Stother is competing in the Prudential Ride London–Surrey 100 on 31 July. Garry's wife, Kate, used to have a stoma and although it was reversed in 2014, Kate still receives support from the **Colostomy Association** including through the closed Facebook group. In order to recognise this support and to ensure others can benefit from all our free services in the future Garry is getting on his bike!

Prudential Ride London–Surrey 100 starts in Queen Elizabeth Olympic Park, and then follows a 161km (100 mile) route on closed roads through the capital and into Surrey's

CONTINUED ON PAGE 21, COLUMN 1

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colostomy association

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Unity is a lottery with a difference. We receive income 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**.

How it works

For just £1 per week you will be allocated a six digit **Unity** lottery number. You can purchase more than one entry if you wish. Every Saturday, the lucky winners are selected at random and the prize cheques posted directly to you, so there is no need for you to claim. You must be 16 or over to enter.

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How to join – three easy steps

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Step two – Select the number of **Unity** lottery entries you wish to purchase per week and how often you wish to play.

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Results & Rules can be checked by visiting
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Or by phoning the Unity winners hotline
0370 055 2291

Calls cost no more than calls to geographic numbers 01 or 02.
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50p
From every £1 goes to Colostomy Association

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

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

1. Your details (please print in block capitals)

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Surname:
Address:
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
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Bank/Building Society
Address:
Postcode:

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

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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:

☐ Payment by Cheque ☐ I enclose a Cheque made payable to Unity (minimum payment £13)

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☐ 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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CONTINUED FROM PAGE 19, COLUMN 3

stunning countryside. With leg–testing climbs and a route made famous by the world's best cyclists at the London 2012 Olympics, it's a truly spectacular event for all involved. The race finishes on The Mall in central London. You can follow Garry's progress and donate at **www.justgiving.com/Garry-Stother**

Suzana's day by the sea

On 17 April Suzana Williams competed in the Brighton Marathon and finished the race in five hours, thirty–one minutes and thirty five seconds. Suzanna also managed to raise **£115** for us, with more donations still to come in.

Climb every mountain update

In issue 40 we told you about Sarah Gregory who will be climbing Ben Nevis in August this year with her partner, Liam. Training has picked up a pace and they are now in the gym four days a week as well as in a running club. You can follow Sarah and Liam's progress and donate at **www.justgiving.com/Sarah-Humphrey8**

It doesn't have to be physical!

Putting a Face to a name

In January the **Colostomy Association** closed Facebook group ran a 'Face to a name' fundraising initiative. The idea was that members would post a picture of themselves on the group and then make a donation at the same time. They managed to raise a brilliant **£205**.

The Archers inspires a new fundraising campaign!

Alex Walmsley launched a new fundraising campaign for the **Colostomy Association** on 19 April 2016. Like many other avid listeners to BBC Radio 4's 'The Archers', Alex was gripped by the news that the show's villain, Rob Titchener, had not only survived being stabbed by his abused wife, Helen, but a stoma had been formed while his bowel healed. This is probably the first time that a leading character in a national drama has been given a stoma!

Alex felt that after the tremendous success of the fundraising for Refuge by 'Archers' listeners, it was time to do the same for another cause that has far less visibility, ours. One listener tweeted: 'If Rob was a nice character he'd have a fund for stoma awareness'. That same evening Alex set up a Just Giving page: 'The Archers' Listeners support everyone with a stoma – except Rob Titchener' **https://www.justgiving.com/Alex-Ashbourne?utm_id=20** Alex also opened the Twitter account: 'Rob's stoma bag' **@bagofthedevil**, to give a voice to the campaign and to those with stomas.

Alex said:

> "It wasn't until three friends of mine had stomas after colorectal surgeries that I learned that it's estimated more than 120,000 people in the UK are in the same position. It's like being a member of a secret club to which no one wants to belong. Despite the British obsession with lavatory humour, people are extremely reluctant to discuss a condition that is far more common than I had ever imagined."

Alex went on to feature in the *Huffington Post* and has helped bring the topic of colostomy out into the open even more! At the time of going to print, Alex has already raised over **£290**.

Special thanks

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 thank you to a few particular people in this edition:

- **The Colorectal Nursing Service at Bedford Hospital** raised **£100** for JOSH at their recent open day. Thanks to the entire team and to Karen Belfield Cockings for arranging the collection.
- **Maggie McIlroy** from Chandler's Ford recently celebrated her 60th birthday with a party organised by her sons and a niece. Instead of gifts, guests were asked to donate to the **Colostomy Association** and a wonderful **£280** was raised!
- **Woodlands Park Adult School** raised **£100**
- **John Brown** from Berkshire raised **£355** through a raffle on his bi–annual coach trip.
- **Joanne McCarthy** from Hertfordshire raised **£133** by holding a pampered chef party
- **Sue Jones** from Saundersfoot collected **£30** from the carrier bag charge in her shop 'Sue's Pantry'

Thank you so much everyone!

You're all amazing!

A thousand reasons to play!

A lucky Colostomy Association supporter has scooped £1,000 through the Unity Lottery!

Earlier this year the Unity Lottery replaced our 500 club and it's been promoted 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 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 20. You can also join online, view the rules and the results by visiting www.unitylottery.co.uk

Irrigation and You

Recently three fellow irrigators have written to share their experiences: Anthony was very keen to begin irrigating as soon as possible and began three months post op, while Linda started a little later once it became apparent her stoma would be permanent. Both are enjoying the feeling of freedom irrigation can give a colostomate. Judith is an experienced irrigator and uses the 'Irypump' to infuse the water.

Anthony writes…

After spending many years in the armed forces both in the Royal Navy and Army Royal Engineers I was determined to keep myself fit, and I did so by running and swimming long distances for many years. On reaching the grand old age of 60 in February 2015 I was feeling proud of myself that I was really quite fit for my age. Then not long after my birthday everything seemed to go downhill!

I had a small amount of blood in my stools and after getting checked out I was diagnosed with colorectal cancer. I was totally shocked and wondered why I'd bothered all these years keeping fit and eating healthily. To top things off when I got my prognosis I was told the cancer was too far down to save my anal passage so I would be having a permanent stoma. The thought of wearing a colostomy bag for the rest of my life made me rather depressed and sad. However, after speaking to the stoma nurses I found out about irrigation which grabbed my attention, although it was subject to my surgery outcome and surgeon consent. Irrigating every one or two days and just wearing a stoma cap appealed to me very much and brightened my outlook.

My cancer was at Stage 1 T2 so they had caught it early. I had my surgery on 25 August 2015 and shortly after that I was told I was now clear of cancer. I was one of the fortunate ones that didn't have to have chemo or radiation therapy. Being quite fit I was soon back on my feet and back to work within six weeks of my operation and running and swimming too.

I was told I could try irrigation three months after my surgery. I didn't waste any time and had the stoma nurses come around just after the three month point to show me how to irrigate. After some initial hiccups I got used to it quite quickly. One of the main things I found was I wasn't getting the temperature of the water correct; by trial and error I worked out that the water I was using was too cool. Once I got that right it has been pretty much plain sailing, with an irrigation taking less than an hour and no late outputs.

I'm now a few weeks into irrigation and I'm over the moon with it. I'm irrigating every other day, using a stoma cap for the first 24 hours and putting a bag on for the next 24 but with no output in my bag by the time of my next irrigation. I will soon feel confident enough to leave the bags alone and just use caps. This is making my life so normal with more freedom and greater control over my bowel movements. I know irrigation won't suit everyone but for me it has changed my outlook for the future.

I suppose the moral of the story is I didn't really waste my time keeping fit; it stood me in good stead for my surgery and also my recovery afterwards. I was quickly back on my feet and back to a normal(ish) life.

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

Linda writes…

In October 2013 I was diagnosed with anal cancer which necessitated a colostomy, performed the following month. For the next eighteen months I managed the colostomy using pouches which needed changing two, three or even four times a day and, despite scrupulous care, still often resulted in pancaking, sometimes followed by leakage. I found leakage a most frightening, embarrassing and demeaning experience if not in the immediate vicinity of a bathroom. Added to this was the constant anxiety of where one could change the pouch if outside the home, the problem of sore skin, the bulging of one's clothing caused by a nearly full pouch etc.

It was decided last year that my colostomy could not be reversed as the muscles in the rectal area had been too damaged by radiotherapy. My stoma was revised from a loop to an end colostomy and I embarked on irrigation. I only found out about irrigation though trawling the internet, but it seemed the answer to leading a more normal life, with the confidence that once evacuation was complete no more output should appear for 24 hours or more. When approached, the stoma nurses were only too happy to help me. They supervised me for two successive days and then I managed on my own, with the comforting knowledge that I could ask them for help at any time.

I have now practised irrigation for seven months and I can truly say that it has transformed my life. Confidence, combined with a more carefree approach to life, has returned. I irrigate about five times a week, usually of an evening as this is more convenient than the morning for me.

For a successful irrigation the person must be relaxed (a warm bathroom helps this), well hydrated (if not the water infused into the gut will be absorbed instead of stimulating peristalsis) and definitely not squeamish! The only negative factor, as far as I can tell, is the length of time it takes to irrigate. I allow an hour although I find 45 minutes is usually sufficient. For me this is a small price to pay for the joy of living a 'normal' life once more. I feel that I am now in control of the bowel, rather than the bowel being in control of me.

I am surprised to hear that only 5% of those suitable actually use irrigation. It is not widely publicised as a means of colostomy management and there seems to be a woeful lack of knowledge within the medical profession. My GP confessed to not having heard of it and even my oncologist only had a hazy idea of what was involved. The stoma nurses in our area are all wonderful, but even they admitted to not publicising irrigation sufficiently.

I feel strongly that all those suitable for irrigation should be informed of the advantages and be encouraged to give it a go. If they then decide it is not for them, at least they will have made an informed choice. At present they make no choice at all because they do not know of any alternative to pouches.

Incidentally, another advantage of irrigation is that of cost. A pouch costs about £3 and it is quite possible to use three or four a day. With irrigation, only one sleeve (cost around £1.25), and one pouch are used each time irrigation is performed. Over the course of the year this represents a saving to the NHS of about £2,000. If 1,000 people were to convert to irrigation over a 10 year period, the NHS could save £20 million. What's not to like?

CONTINUED ON PAGE 25, COLUMN 1

Editor's note

The **Colostomy Association** promotes irrigation at the annual conference of the Association of Stoma Care Nurses and in e–newsletters sent out to stoma care departments throughout the year.

CONTINUED FROM PAGE 23, COLUMN 3

Judith writes…

Some of you may have read my article in *Tidings* some years ago on the B. Braun Irrimatic irrigation pump. If so, you will remember my great enthusiasm, tempered inevitably, by the fact that it wasn't on the Drug Tariff and cost a considerable amount of money. For several years, B. Braun had promised another that would be available on prescription and it finally became a reality in November 2014.

'Irypump' is smaller than the original Irrimatic, so that makes it much easier to transport – I've had mine for about eighteen months and it's already been to Sri Lanka, Gran Canaria, France several times as well as odd nights or weekends away in the UK! It's most recent 'exploit' was by torch–light on Easter Morning, during a power–cut!

It's an oval 'jug' measuring about 12cm in height (extendable by an extra 8cm, when in use to hold up to 2 litres), 20cm in width and 10cm in depth. It comes with a tube and cone like the 'hang–up' kits and a black plastic carrying case and only has to be charged from the mains every five to six weeks (for daily use). You just sit it at your feet or on a table beside you, insert the cone into your stoma through the irrigation sleeve in the normal way, turn on the switch and instil the water at a suitable, steady speed. Although the pump does not heat the water, there's a temperature gauge in the base.

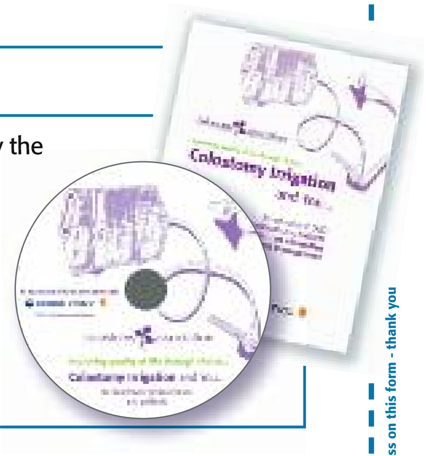
So the irrigators amongst you (present or potential) are asking "where's the catch?" I have to admit, I was sure my doctors' practice would never be prepared to finance it, but there was no problem at all. Certain GPs have posed more questions than others, but many were more compliant when they fully understood the advantages of the pump for their patients and the eventual savings involved by irrigating generally. So you see, there is no catch!

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

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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 42cm × 28cm 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 will receive a large canvass of her photo for first prize, while the two runners up will each receive a free calendar of their own to use and as a keepsake.

Why not get your Christmas gifts sorted early and order your Colostomy Association calendar(s) today? 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**.

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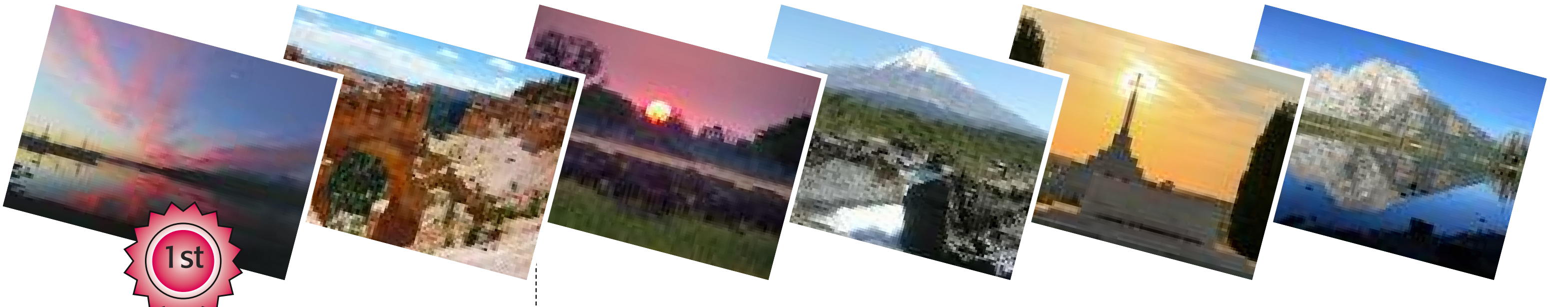
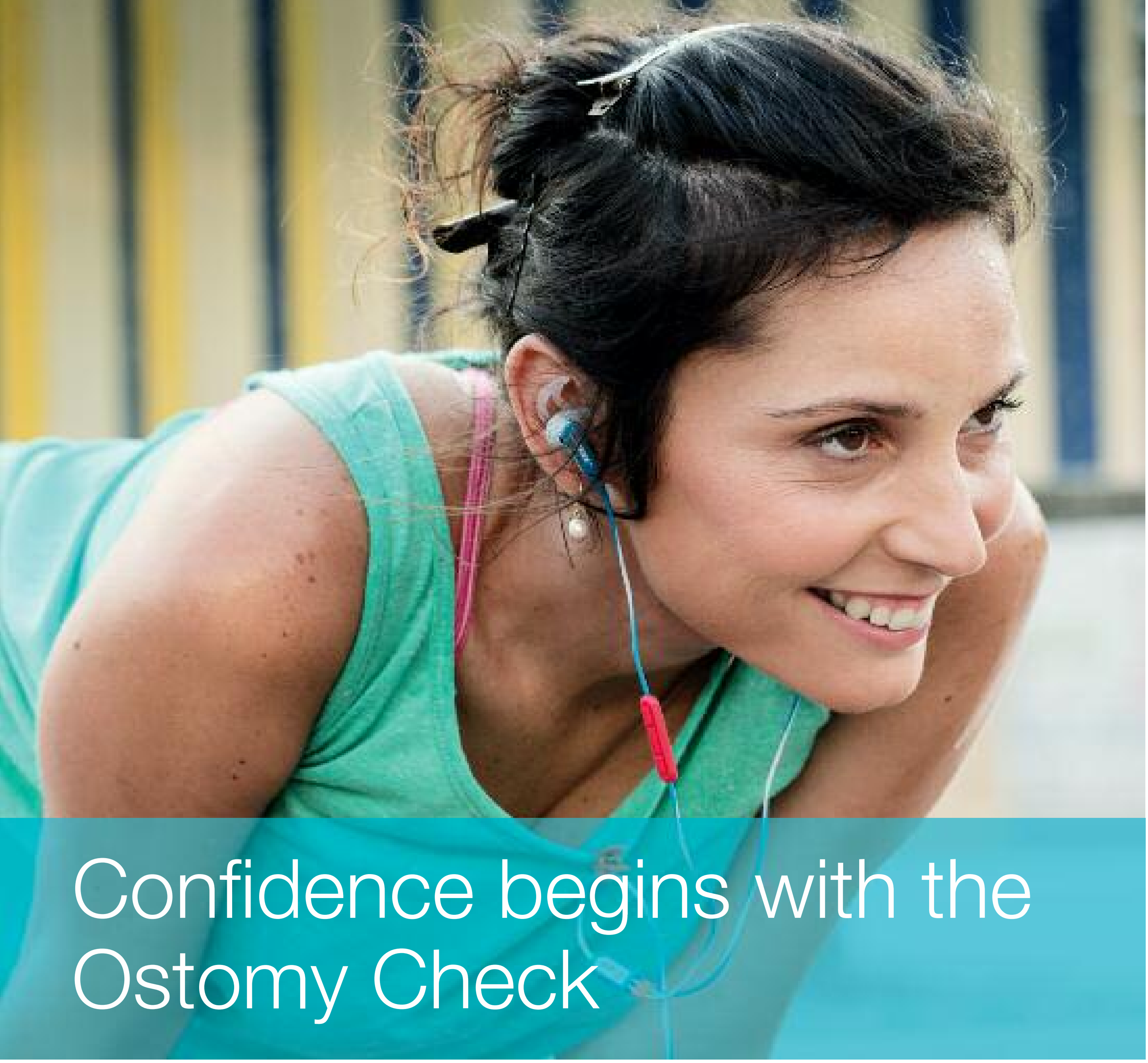



Confidence begins with the Ostomy Check

Quality of Life Survey

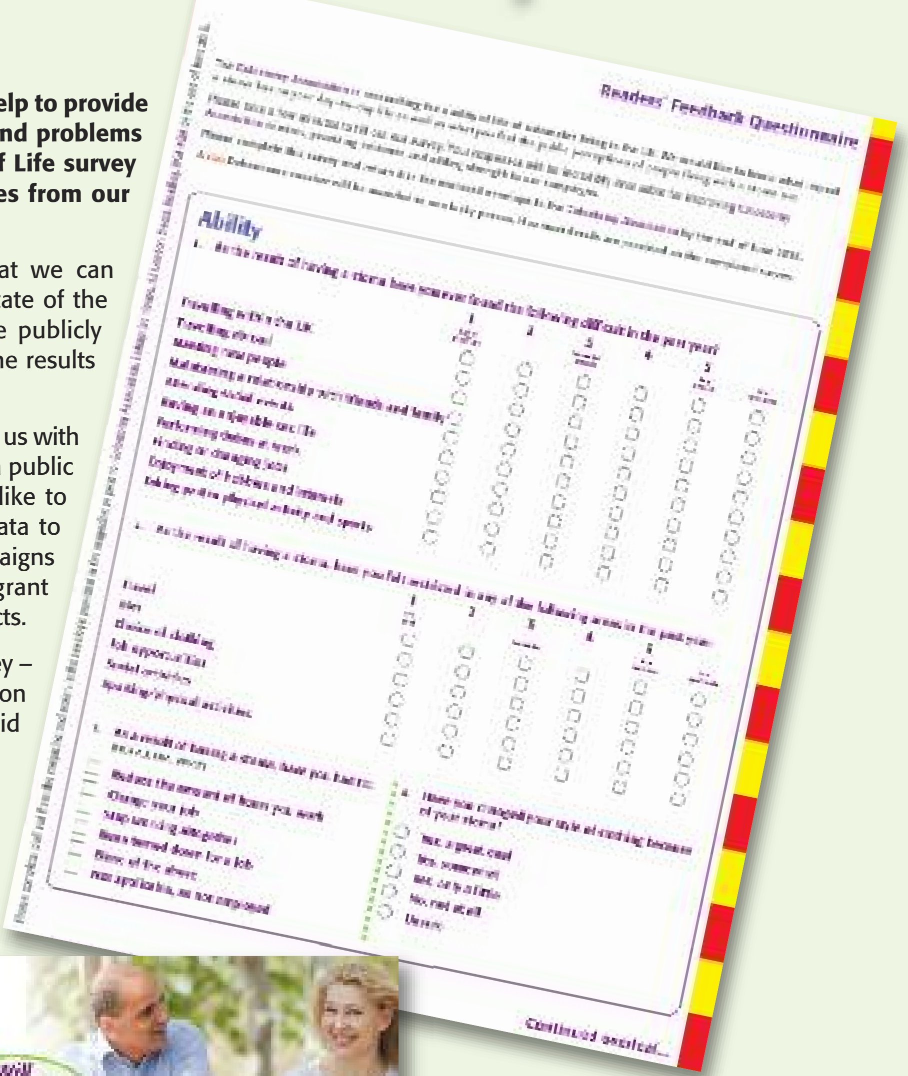
In the last edition of *Tidings*, we asked for your help to provide us with evidence of the main concerns, issues and problems you faced in 2016. The reaction to our Quality of Life survey has been incredible, with hundreds of responses from our readers.

These responses are now being analysed so that we can produce a comprehensive report on the current state of the ostomy community in the UK. This report will be publicly released in a few months' time, so expect to see the results online and in print later in the year.

If successful, the results of our survey should provide us with the hard facts needed to have a powerful impact on public perceptions and to raise awareness of what it is like to have a stoma. Additionally, we plan to use the data to improve our current services, influence future campaigns and as evidence for composing compelling grant applications to raise vital funds for additional projects.

Thank you to everyone who has completed our survey – especially those of you who placed your own stamp on the RSVP envelope. Around a third of our readers did just that, saving us vital funds. Much appreciated.

Stay tuned for the results later in the year!



Readers' Feedback Questionnaire

Ability

Continued overleaf...

Would you like to spread the word about the **Colostomy Association**? Please help us to do just that!

This issue of *Tidings* contains a special A4 sized poster that can be displayed in a variety of locations to signpost people to the free advice and information available from the **Colostomy Association**.

The **Colostomy Association** currently provides invaluable support to over 23,000 people living with a stoma. However, with your assistance we can reach out even further and ensure that more people than ever are able to live a full and active life.

Happy to help out?

Please take the poster to your local surgery, pharmacy, corner store, library or stoma care department or simply pin it to your local noticeboard. (You may need to ask for permission to put it up.) Please let us know where you've displayed your copy or post a picture of it onto our closed Facebook group or on Twitter and tag **@colostomyassoc** to promote your efforts.

If every one of our 23,000 supporters manages to display one poster and if every tear off slip is taken, we have the potential to reach literally tens of thousands more people! Help us to help others. Telephone: **0118 939 1537** for more stocks or email the quantity needed along with your postal address to **cass@colostomyassociation.org.uk**

Thanks so much!

Update on **stoma care products** and **services**

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

NEW

The **Riksack** from **Stomaworks, the secure emptying and changing system for anyone with a stoma.**

It can be used at home or on the move.

Simply attaches around the waist for use in the standing position.

Made in the U.K and sold by: **http://stomaworks.co.uk/**

3M™ Cavilon™ No Sting Barrier Film

For gentle yet effective protection to the delicate skin around your stoma.

Use a Cavilon no sting barrier film wipe every time you change your appliance to protect against adhesive damage and to prevent and treat sore skin.

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COLOSTOMY DAY 2016

Fight the Poo Taboo

Join us and thousands of ostomates up and down the country on Saturday 1 October 2016 for Colostomy Day – our own national awareness day to help end the stigma of having a stoma and give ostomates back their voice.

Do you find it difficult to talk to people about your stoma? Thousands of adults and children across the UK live in silence due to fears of speaking out about theirs.

Despite recent improvements in public awareness and perceptions of ostomates, too many people with a stoma are still left feeling isolated and unable to talk about their condition due to the lack of public understanding or fear of potential acts of discrimination.

On Saturday 1st October 2016, we want you to help us smash the stigma of having a stoma by staying silent or by making as much noise as possible. Colostomy Day is a once–a–year opportunity to help raise awareness and challenge perceptions of what it actually means to live with a stoma.

Speaking about **Colostomy Day 2016**, Giovanni Cinque, our Development Officer, said: “No one with a stoma should have to live in silence. We have made great strides forward in tackling public perceptions and the stoma stigma but we still have a long way to go. Colostomy Day will provide a nationwide platform for adults and children or family members affected by stoma surgery to make a stand. We are expecting dozens of supporters across the UK to get involved by either making some noise or by staying silent. Make sure you’re involved so we can maximise on the impact.”

“I speak out about having a stoma because sharing my experience has helped others going through the same thing as I have been through.”
– **Thaila Skye**

Would you like to join us in the fight against the poo taboo this October? Here are some of the ways you and your family or friends could get involved:

MAKE SOME NOISE!

Smash the stigma by making as much noise as possible – don’t let yourself be silenced about your life with a stoma. Some ideas for making noise include busking or holding a choral event, wearing an over–the–top outfit that will grab people’s attention, telling your story on social media or speaking openly to the press in your area.

STAY SILENT!

“It isn’t easy to talk to people about having a stoma – most people either don’t understand the condition or don’t know anything about it. I’m staying silent on Colostomy Day to highlight why it can be so difficult for ostomates to tell their friends, family or colleagues about their stoma.”
– **Dean Armstrong**

Highlight the fact that many ostomates find it hard to talk about their condition by staying silent on Colostomy Day. Some ideas include holding a sponsored silence, organising a silent disco, running a silent auction, or challenging yourself to stay off social media for an hour, a day or even a week and making an announcement about why you’re doing so.

Make some noise or stay silent – how will you get involved?

CONTINUED ON PAGE 33, COLUMN 1

CONTINUED FROM PAGE 31, COLUMN 3

What are some people doing for Colostomy Day 2016?

Caroline Bramwell – Devon

Caroline had surgery for ulcerative colitis seven years ago and now has a stoma, but having a 'bag for life' is not stopping her. From being a non–swimmer two years ago, her desire to become fit after surgery is now helping others and on Friday 30 September 2016 Caroline's inviting ostomates to join her in the pool at Sidmouth Harbour Hotel Spa in Devon.

Speaking about Colostomy Day, Caroline said: "I meet so many ostomates who have lost confidence in getting out on the beach or into a swimming pool. Having an ostomy doesn't need to stop you doing the things you enjoy but I appreciate that it does take time and confidence. That's why I am welcoming others to join me for a social get together."

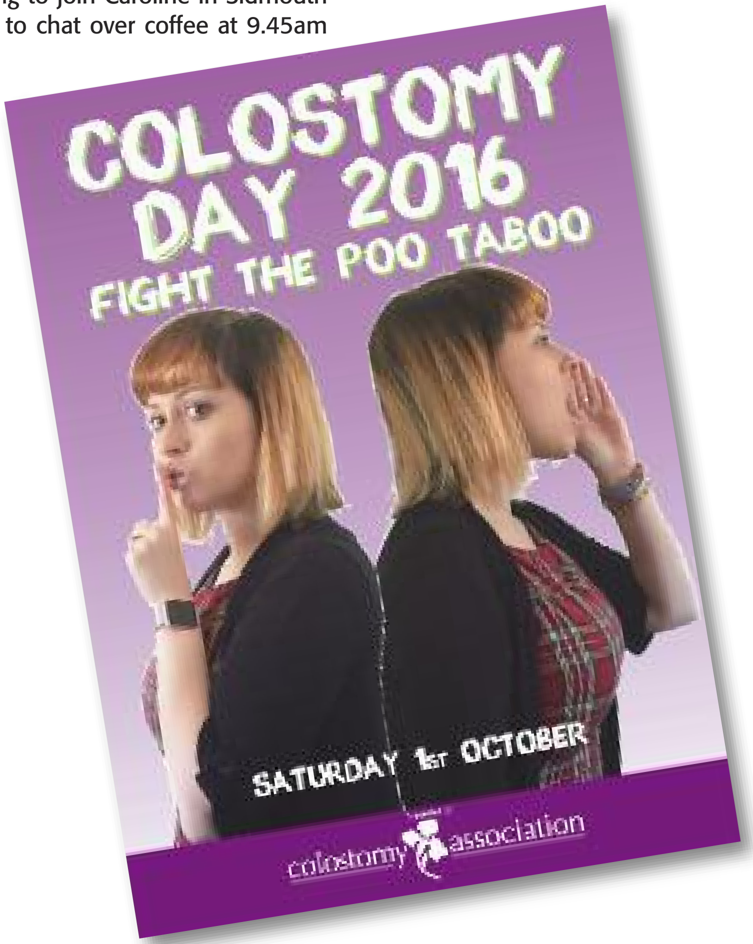
Those wishing to join Caroline in Sidmouth will be able to chat over coffee at 9.45am before heading into the hotel pool at 10.30am on that Friday morning. There is no pressure for anyone to go beyond what they are comfortable with, but with Caroline's experience of swimming 5km per week in her training, she'll be there to share her own experiences and to help with any questions.

Caroline can be contacted by email at **caroline@theoldengroup.com** or on **01271 375393** for further information.

Caroline Emeny – Norwich

A group of brave ostomates plans to take to the streets in Norwich City centre on Saturday 1 October 2016 to make some noise and help create a stoma–friendly society.

Colostomy Association trustee, Caroline Emeny, and her team of protesters hope to grab the attention of the general public in Norwich with individuals staying silent, holding placards and speaking out to people about the poo taboo.



Speaking about the event, Caroline said: "We plan to create some noise in Market Hill, Norwich City centre for several hours with an active group of ostomates, getting the attention of the Saturday crowd, and making people aware of the issues involved with living with a colostomy."

If you fancy joining in, simply turn up between 11.00am and 3.00pm to offer your support to Caroline and her team or ring Caroline beforehand on **0789 9857351** for confirmation!

How will Colostomy Day make a difference?

There are more people living with a stoma than you might think. It is estimated that almost 1 in every 500 people in the UK have a colostomy, ileostomy and/or urostomy but many feel uncomfortable about talking about their condition due to fear of embarrassment or misunderstanding.

The past few years have seen some incredible improvements in public awareness and attitudes towards people who live with a stoma but we still have a long way to go to change the mindset of the general public. These improvements have come about thanks to brave individuals, fed up with living in silence, speaking out about their condition on social media, in the press or just to their friends and family.

As more people speak out about living with a stoma, even more positive changes will result through greater public awareness. Colostomy Day is a fantastic opportunity to make a difference and help improve the lives of thousands of people across the UK. Help us make each Colostomy Day a huge success and look out for an update in our Autumn edition.

Interested in taking part? If you, your family or friends would like to get involved with **Colostomy Day 2016** then please get in touch and request a free information pack with lots of ideas on what you can do to help fight the poo taboo. Once your event is registered with us, we'll publicise your efforts via the Colostomy Day page on our website and via our social media, and we can also try to help promote your activity in your local media.

Alternatively, if you'd like to get involved with the activities in Sidmouth or Norwich mentioned above, please get in touch with the respective organiser. They'd love to have your support on the ground!

A big thank you goes to everyone who has agreed to run an event for **Colostomy Day 2016** so far – this third year promises to be even bigger and better than before. Contact the **Colostomy Association** on **0118 939 1537** or **cass@colostomyassociation.org.uk**

Speaking out…

..on 'Ostomonday'

Ostomy Bags Are Not Just For Old People | Ostomonday

In today's world, there are lots of YouTubers out there creating amazing content online; from fashion and beauty, to gaming and even film–making. However, the topics of many of the videos on *my* YouTube channel are not often found in the 'mainstream'.

That's because I make videos on YouTube about my life after having ostomy surgery.

Let me rewind a little

After several years of ignoring symptoms such as extreme and unexpected weight–loss, fatigue, abdominal pains and blood in my stool, I was dragged to the hospital by my mum and I saw a gastroenterologist. I was diagnosed in 2009 with Crohn's disease, and I had lots of scans and tests to examine the extent of the damage caused by my disease. One of those tests was a colonoscopy and I spent the entire procedure crying and wailing because every single second was horrifically painful. Not long after the colonoscopy, my physical and mental health rapidly deteriorated and an MRI scan revealed a perforated colon. Little had I known, I had been at home with sepsis for a few weeks.

In March 2010, two badly damaged sections of my colon were removed. I woke up with a midline incision wound, a drain, an ileostomy from my small bowel (which I named Stan) and, to expel mucus from the remaining section of my colon, a mucous fistula (which I named Colin). Why did I name them? For the same reason I name a spider when I see one – to make them seem less scary.

For the first few days, I was in total denial. I didn't want to get out of bed or see anyone. Over the next week or two, I started feeling better and not being in as much pain, so I began to feel more positive and that this was a *good* thing. However, when my midline incision wound reopened and it had to be packed and dressed daily, it took a lot of strength and determination not to let it bring me down. In the end, it took seven months for everything to be completely healed, so that was a long recovery!

Once I'd gotten my head around having a stoma to manage, and I started to see the giant valley of a wound down my abdomen gradually healing, it got less scary. Again, I started to feel more positive about my situation. My energy was increasing, I was gaining weight again, I wasn't feeling *any* of the 'Crohnsy' abdominal pains that I had been experiencing for years prior to the surgery. Every day was a little easier, and even though there were lots of bad days (mostly due to leaks or sore skin), the good days certainly outweighed the bad days. Life with a stoma wasn't actually as bad as I thought it would be.

Raising Awareness on YouTube

My ostomy surgery gave me a second chance, and I didn't want to waste it. Since I had regained all the weight I had originally lost (plus a lot more) and had much more energy, I decided to start living a healthier lifestyle and be more active. I originally started my YouTube channel to document my diet and fitness, to try and keep myself accountable. It was after a while of making these weekly video blogs (or 'vlogs') that I decided to talk about another aspect of my life; of having a stoma.

That's when I created the YouTube series 'Ostomonday'. I wanted to spend one day a week dedicated to talking about what it's like having a stoma. Not only did I want to raise awareness to the general public of what a stoma is and what it's like having to wear ostomy bags, but also I wanted to help anyone going through anything similar to myself. Back when I had my surgery and during my recovery, there wasn't much in the way of people talking openly about it on social media. There were a few people blogging about it over in the US and in Canada, but certainly not much presence in the UK, and not on YouTube as far as I know. So I decided to start the conversation.

I've been able to raise awareness in The Independent, on local TV and radio, and even got the chance to speak at the European Medtech Forum in 2015 about how the medtech industry needed to treat the people using their products and devices as people, not just as patients or as just another number on a spreadsheet.

..and on Colostomy Day

"Why 'Ostomonday'? Why shouldn't it be every day?"

Well, it was either 'Ostomonday' or 'PooTube'. But all jokes aside…the reason I decided to keep it to one day a week rather than talking about it every single day was simply because I don't want to be defined by my stoma. Sure it's a big part of my life, but there are other things in my life that make up the person I am: married to an *amazing* man, I love watching movies, I am a huge geek when it comes to the TV show Red Dwarf, I have a slight addiction to cups of tea and I am currently researching my family tree. So while I have my stoma 24/7, 365 days of the year, I have other things going on in my life too.

Sure, every day *could* be seen as Ostomonday, Ostotuesday, Ostowednesday and so on, but I just don't want to spend every waking second thinking about it, otherwise I'll never get anything done! The point of having ostomy surgery was for me to *live my life*, so that's why Ostomonday came about – the other six days of the week, I can just get on with life.

Being Part of an Amazing Community

In the last four years of making YouTube videos, I've received hundreds of messages and emails from people sharing their own stories. It's incredible to hear such diverse experiences and I'm truly honoured to be given an insight to so many people's lives. I have seen so much strength and courage from people who, when I first hear from them, are absolutely terrified about having a stoma, but then I hear from them months after their surgery and they are full of life and positivity. Of course, there are some people who have messaged me who still struggle to accept having a stoma, and that's okay too. All I can do is tell them about my experience and hope that something, even if it's just a tiny nugget of information, can help make their lives just a little bit easier that day. I'm so glad to see that there are more and more people blogging and speaking out on social media about having a stoma, which means there's so many more resources out there to point people to. Bloggers such as Jess from **uncoverostomy.org**, Eric from **veganostomy.ca** and Sam from **sobadass.me** have become invaluable, not just to me, but to a lot of people out there. And those are just three people out of so many more ostomates out there, doing incredible advocacy work.

I honestly think that people who have a stoma are some of the bravest and strongest people in the world. There is still such a stigma around bowel–related topics, and it can be very difficult to accept such a big change to your body. However, most people I talk to have found the positives in their experiences and celebrate every single victory – even if it's something as simple as going to the nearest café for a drink with their friends.

I'm due to have some more surgery very soon, this time to reconnect my small bowel to my remaining section of colon, and to create a colostomy. So my mucous fistula (Colin), will then be known as 'Colin the Colostomy'. I'm actually feeling pretty positive about it – if it wasn't for the incredible support and resources there now are, I would be terrified, as I don't know that much about colostomies really, mostly just ileostomies! But being able to ask this incredible network of people via social media about their experiences with a colostomy, and especially the fantastic resources on websites such as the **Colostomy Association** website and in *Tidings* magazine, has all helped me prepare for what to expect.

It's not exactly the most glamorous topic, I know

Being someone whose face is instantly associated with ostomy bags probably isn't the sort of thing you'd choose to do with your life. I certainly didn't expect my life to turn out this way. But it did, and I decided to make the most of it. And I'm glad I did. ■

Follow Thaila:
Blog: **thailaskye.me.uk**
Twitter: **@ThailaSkye**


Tube Belt

Fashion Show Models Needed

On Saturday 16th September 2017 the Colostomy Association bi–annual Open Day will be focusing on our 50th anniversary by going back to our original roots in 1967 as the Colostomy Welfare Group. Our open day will take place at Wokefield Park near Reading (pictured above) and the celebratory event promises to be another wonderful opportunity for people to benefit from a wide range of exhibits, topical talks, SCN appointments and more…

As part of the celebrations we will be holding a Fashion Show to demonstrate that having a stoma doesn't stop you looking good and feeling great.

We are now recruiting volunteer models of all ages, sizes and backgrounds to take part in this exciting event. You don't need to be the next Kate Moss to get involved but you do need to have a colostomy.

Our Ostomate Fashion Show will help demonstrate that you shouldn't have to feel restricted with what you wear. We will be showcasing outfits for a variety of situations from beachwear to glamorous nights out.

Our 2015 Fashion Show was a huge success – all thanks to our sponsored image consultant and hair & beauty team, as well as our wonderful team of volunteer models aged 11 upwards. Both the audience and our models had a great time, with an electric atmosphere and so much clapping that people had sore hands. Our models even had a standing ovation!

It can be nerve–wracking to 'strut your stuff' on a catwalk in front of more than 200 people but it can also be fun. Don't take our word for it: have a look at these quotes from several of last year's models:

Faye

"It was an absolutely amazing feeling. I was so nervous (and hungry) beforehand but the experience most certainly boosted my confidence. The best part was at the end when numerous people came up to me saying I had helped them so much in the space of five minutes…that was so overwhelming."

Steve

"A frightening prospect that became an awesome experience and had me buzzing! Can I have another go, please?"

Ron

"Without a doubt one of my most exciting and rewarding experiences in recent years. I enjoyed every minute and am sure all who took part felt the same. I'd love to take part again." ■

How to volunteer

If you would like to be put forward for consideration as a model then please get in touch by calling **0118 939 1537** and speaking with Jo McKenzie, our Senior Administrator, or by emailing **cass@colostomyassociation.org.uk**. We hope to hear from you soon!

Further information about our special 2017 open day event will follow in a future edition of *Tidings* so look out for details and a booking form nearer the time.

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GENERATION

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Life’s Curves

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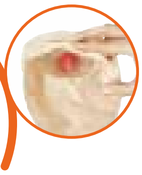
By providing gentle pressure close to the stoma, NovaLife Soft Convex helps push the stoma into the pouch and fits the natural folds of the body – creating an enhanced seal.

93%

find the barrier ***easy to remove***



95%

said ***EasiView viewing option*** is important for pouch positioning

95%

are satisfied that the ***skin barrier*** provides a good seal between stoma & skin

YOUR FREE SAMPLE

My stoma size is ______________________ mm

My current appliance is ______________________

☐ **Ileostomy** ☐ **Colostomy** ☐ **Urostomy**
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dansac
Dedicated to Stoma Care

Stoma Friendly Society

We believe that everyone with a stoma should have the right to live a full and active life. As the UK's largest stoma charity, we are championing the need for a stoma–friendly society – where any adult or child with a stoma in the UK is able to live without isolation, stigma or discrimination.

Since launching our campaign in January this year we have already achieved several big successes in our mission to create a stoma–friendly society as reported in the previous edition of *Tidings*.

Find out more about what the **Colostomy Association** has been doing to help improve the lives of tens of thousands of people living with a stoma across the UK.

Building connections

As we campaign to create a stoma–friendly society, we have been building relationships with other charities, organisations and groups who are already working tirelessly to improve facilities. We have linked with Changing Places who campaign for accessible toilets that are suitable for people with a variety of different conditions.

We have also started working with organisations like Attitude is Everything and United Discriminates who try to make live music and sport available for people regardless of their condition and ability.

We met with Rob Wilson MP (pictured here on the right with our Marketing Communications Officer, Niall Norbury) earlier this year to see if he could help us improve toilet facilities in Parliament and he has since been in conversation with the Centre for Accessible Environments who help make buildings accessible to all.

Additionally, in Scotland we have partnered with the Grace's Sign campaign – a one–person campaign to change the symbols of accessible toilets so that they represent the variety of people who use accessible toilets. Grace, aged only 10 years old, has found recent success with her signage being added to toilets in the Scottish Parliament.

Improving toilets

Some people with a stoma feel isolated and unable to go out and enjoy themselves due to inadequate toilet facilities. The **Colostomy Association** has been campaigning to ensure that toilet facilities across the UK meet the needs of people with a stoma.

Since launching our stoma friendly loos campaign a number of organisations have already come on board including the popular restaurant chain – Côte Brasserie – and the Glastonbury Festival.

The **Colostomy Association** is proud to endorse these organisations as having stoma–friendly loos. This means that if you visit one of their accessible toilets you should find a hook on the back of the door, a shelf or surface space to change your bag and a disposal bin in each cubicle.

These small additions can make a huge difference and will enable more adults and children to go out and enjoy themselves without the fear of wondering whether there are any suitable toilets nearby.

We are developing links with other organisations which we hope will also make the necessary changes so that their loos are more stoma–friendly too. Look out for an update in the next edition of *Tidings*. If you would like to help us make some improvements in your local area, then please get in touch.

Fighting the stigma

Our work around toilets has not been limited to changing facilities – we have also been campaigning to improve public awareness of the right of ostomates to use accessible toilets.

While many people with a stoma are able to use standard, non–accessible toilets – some ostomates benefit from the extra space and amenities that accessible toilets provide. Sadly, some people with a stoma have faced outright hostility or anger for using 'disabled' toilets from people waiting outside, despite their right to use one.

In Spring 2016, the **Colostomy Association** launched its #MyLooToo campaign which saw people share their worst accessible toilet experiences, giving them an opportunity to voice their right to use accessible toilets without fear or reprimand or recrimination.

The campaign was incredibly successful with individuals' stories shared hundreds of times on Facebook and Twitter as well as publicity in newspapers. If you've ever experienced issues then please post your own stories online with the hashtag #MyLooToo.

Your courage and bravery is making a huge difference to public perceptions and the word 'colostomy' is now becoming more widely used in society. People are gaining an understanding of what it's like to live with a stoma and how it affects so many people's lives – of all ages.

CONTINUED ON PAGE 41, COLUMN 1

Caroline Richards

CONTINUED FROM PAGE 39, COLUMN 3

Colostomy Association supporters Caroline Richards, Lottie Bennett and Dean Armstrong had their stories featured in online, local and national publications including *The Mirror*, *The Independent*, *Daily Mail*, *Metro*, The *Huffington Post* and *Real People* magazine. By sharing their stories, these supporters have helped challenge the stigma of having a stoma.

If you'd be happy to feature in a national magazine or local newspaper, please let us know as we can write up your life story or produce a compelling press release. We'll handle your story sensitively and will even contact the media on your behalf. If you'd rather feature in *Tidings*, that's fine too! Your story can be considered by the editorial team at one of our quarterly meetings – so do get in touch.

Dean Armstrong

Training airport security staff

Ostomates travelling across the world this summer may have noticed improvements in the knowledge and empathy of some airport security staff. If you have noticed any positive changes, it might be because the **Colostomy Association** has been training and educating airport security staff on the needs and concerns of people with a stoma.

Travelling through airport security can be distressing for adults and children with a stoma who are at a higher risk of being searched. The fear of airport security staff not understanding their condition or reacting in a negative way can put ostomates off travel altogether.

We felt urged to act after receiving complaints from supporters who had faced prejudice, misunderstanding and embarrassment while passing through airport security. Unfortunately, these isolated incidents can often put off ostomates from travelling abroad in the future so we felt something had to be done.

The **Colostomy Association** has been delivering workshops at a variety of UK airports including Luton, London City and Birmingham to educate security staff from the perspective of a traveller who has had stoma surgery and may be wearing a stoma bag or stoma plug. Our training has helped security staff better understand what a stoma actually is, what a stoma does, what a stoma bag or plug looks like, how a person with a stoma can feel while being searched in public, as well as how their attitude and behaviour could help reduce the risk of embarrassment for travellers.

Monty Taylor, Chairman of the Trustees said: "It is positive to see so many airports agreeing to train their security staff on how to react and respond to ostomates. We understand that in a period of heightened security that ostomates are more likely to be searched. Our training will not decrease the chance of people with a stoma being stopped and searched but will ensure they are treated with respect and dignity."

Lottie Bennett

The response from staff who undertook the workshop has been incredibly positive and we hope to branch out our educational training to other airports across the UK.

Speaking about the training, Bob Collier from Luton Airport said: "All our staff learnt a great deal from the experience. Luton Airport is keen to progress a clear respectful process of engaging with ostomates who use our facilities, as well as to continue to liaise with the **Colostomy Association** to ensure we all benefit from our experiences of airport security."

In addition to the training, the **Colostomy Association** provides a free travel certificate explaining a stoma in a variety of languages. The aim of the certificate is to help avoid confusion for ostomates when travelling in foreign countries. A copy can be obtained from the office by calling **0118 9391537** or by emailing **CASS@colostomyassociation.org.uk**

Going to a Music Festival with a Stoma

When I was younger, I'd never camp at music festivals. Even though I've loved music since I was a teenager, have been playing in bands since my early twenties and even once played at the *Latitude Festival* in Suffolk, I never thought camping was something I could actually do. As a teenager all my friends went off for festival experiences whilst I stayed at home. I remember looking wistfully at the line–ups for *Reading* and *T in the Park* and watching *Glastonbury* on TV, wishing that I could be there. But I thought that, as someone with a need for a bathroom with running water for an hour a day to irrigate my bowels, camping at music festivals was something I could never do.

I was born with an imperforate anus and had a colostomy up until the age of three when I had an operation to create an artificial anus. The muscles controlling my bladder and bowel still don't work as they should. This means I have to self–catheterize to pass urine. From the age of 11, I irrigated my bowel by introducing water through the anus. Then, when I was 14, a stoma was formed so water could be introduced directly into the colon to stimulate the bowel to empty. This process is commonly known as Antegrade Colonic Enema (ACE)

Instead of camping I would buy day tickets for *Reading Festival* or go to *Primavera* in Barcelona, a city–based festival where everyone stays in hotels or apartments. But nonetheless I always regretted missing out on the camping experience.

Last year at the age of 33, I applied to become the festival project manager at *Attitude is Everything*, a charity committed to improving deaf and disabled people's access to live music. My role would be to work with music festivals to advise them on how they could become more accessible for all disabled people. Some of my friends were amused that I'd applied for this job despite the fact that I'd never camped at a music festival. However, I felt this missed the point – the fact that I had direct experience of the barriers disabled people can face at these events made me the ideal person. Luckily the charity seemed to agree and I started work one week before last year's *Glastonbury* festival, which would be my first ever camping experience.

Glastonbury was fantastic. The access facilities at the festival are superb and include a High Dependency Unit (HDU), which is an accessible mobile bathroom with running water, plenty of space, shelving space for equipment, a hoist and changing table for those who need it. HDUs really do make an inaccessible music festival accessible. *Latitude* and *Reading* festivals now have them and other festivals are starting to follow suit.

It's true that HDUs are not absolutely perfect. For the irrigation procedure I need to hang equipment over a toilet and there are no hooks so I have to improvise. Whilst there is hot water, there certainly isn't enough of it for my irrigation. Luckily *Glastonbury*, *Latitude* and *Reading* all have sources of boiling water available on the accessible campsite area so I was able to mix that with cold water to get the correct temperature. It's hard to collect the hot water and set up the procedure simultaneously, so I now take a personal assistant with me to help. Many festivals provide personal assistant tickets free of charge.

At times when I wasn't feeling too great after irrigating or didn't feel comfortable standing in a crowd I was allowed access to the viewing platforms which are reserved for wheelchair users, people who can't stand for long periods or anyone else who might need them. I was also allowed to use the accessible toilets which are now becoming more common at music festivals. For example *Festival Number 6*, a four day camping festival in North Wales, is held in the village of Portmeirion and there are a number of plumbed in accessible toilets on site. As such, it's a really ostomy–friendly music festival!

Challenges certainly remain at many festivals for people with disabilities and for ostomates but, since I've been in my role, I've been really impressed by the amount of good practice. Lots of festivals have access information on their website and contact details for access officers, who are committed, supportive and work incredibly hard to meet individual access requirements. I understand as well as anyone the fears that ostomates have about camping at festivals but I would recommend any music–loving ostomate to look at the festivals out there as you may be surprised at how accessible they can be!

Paul Hawkins
Festival Project Manager

Attitude is Everything

respond
making life better

a dedicated delivery and support service.

Simon & Caroline's story

After joining Respond's home delivery in February, 7 year old Simon and his mum Caroline are back on track and supported every step of the way!

Following Simon's operation in the Royal Belfast Hospital for Sick Children, his mum Caroline had a number of problems ordering and receiving Simon's prescription from their supplier. On one occasion Simon ran low on supplies and on hearing this, another patient recommended Respond Healthcare.

Caroline had never heard of Respond before, but got in contact and was put through to Samantha Glenn in the customer support team. Samantha was able to explain how Respond could order prescriptions on Simon's behalf and deliver it directly to them. Samantha also explained about the regular order service that Caroline and Simon could use and have now joined.

"I felt completely reassured"

Following the issues they had previously experienced, Caroline was really happy to be put in touch with Respond. "Samantha was lovely, down to earth and understanding, she listened to my concerns and was very clear about what Respond could do to help and she has certainly kept her word".

They also found the process of changing to Respond very easy. Caroline said the process was "hassle free and removed the stress I was under before".

In addition Caroline explained that she finds the service "completely simple, literally one call" and that additional benefits have been that "deliveries are discreet and left where agreed".

"It has made a huge difference to our lives"

Finally Caroline says "I praise Respond for their Customer Service. I would recommend them to anyone in a similar situation".

making life better

respond might be a new name, but we have been helping make life better for thousands of stoma patients for a long time.

Part of the family-owned Eakin Group – we have been specialists in ostomy care since 1974. We champion quality of life for people living with a stoma, putting your care at the heart of what we do. We listen to you and respond to your needs.

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0800 028 6848

hello@respond.co.uk
respond.co.uk

Come and say hello
f respondltd
@respondltd

signing up is easy

step 1 - Call our friendly support team, send us an email or visit our website.

Make sure you have your full contact and GP details and the prescription items that you'd like to order to hand.

step 2 - We'll contact your GP directly, where possible, to get your prescription. As soon as this is received, we will send your order out and be in touch.

step 3 - Now you can sit back, relax and look forward to your parcel arriving. All our orders are sent in discreet, unbranded packaging.

HiLINE OstoMART

an eakin company

Stoma Aid gets boost from UK Support Groups

Since launching, Stoma Aid has received thousands of unneeded stoma supplies from patients and manufacturers to help ostomates across the world who cannot afford or access the ostomy supplies they desperately need.

Support groups across the UK have been helping us achieve our goal through their incredible kindness and generosity.

Here are just some of the ways support groups have been helping ostomates benefit from Stoma Aid across the world:

Wessex Stoma Support Group

Members of the Wessex Stoma Support Group have donated their genuinely unwanted stoma supplies to Stoma Aid – generously covering the cost of transporting them to our warehouse in Bolton.

A van full of much–needed supplies made its way to the Stoma Aid warehouse in Bolton where they were sorted and then shipped to people in need through partner UK organisations.

Speaking about the donation, Ken Edwards from the Wessex Stoma Support Group said:

> "Part of our group's charitable outreach work is to help people where stoma supplies are unavailable or too expensive. This problem stops those living with a stoma in developing countries having the quality of life that they should have."

Stevenage Ostimistics

Ostomates from the 150–member strong Stevenage Ostimistics group have not only been donating much–needed supplies to Stoma Aid but have been acting as a central collection point for anyone who can't send genuinely unwanted supplies up to Bolton.

Alfred Levy, co–organiser of the Stevenage Ostimistics and **Colostomy Association** Trustee said:

> "It's easy to forget how lucky we are in the UK, we are able to receive supplies at little or no cost, we have access to excellent stoma care nurses and there are plenty of support services for people with a stoma. Thousands of ostomates in developing countries are not so lucky – our donation will help make a real difference to stoma patients across the world."

Coventry Stoma Support Group

For over six months members of the Coventry Stoma Support Group had been collecting their unwanted stoma supplies ready for the launch of Stoma Aid.

In total, the group donated over 450 unwanted ostomy bags which will help ensure hundreds of patients in countries like Moldova, Kosovo, Uganda and Papua

New Guinea are able to access the supplies they desperately need.

Martin Robbins, organiser of the Coventry Stoma Support group said:

> "We are very proud to have donated to Stoma Aid and we hope that our surplus supplies will be able to benefit those less fortunate than people living with a stoma in the UK."

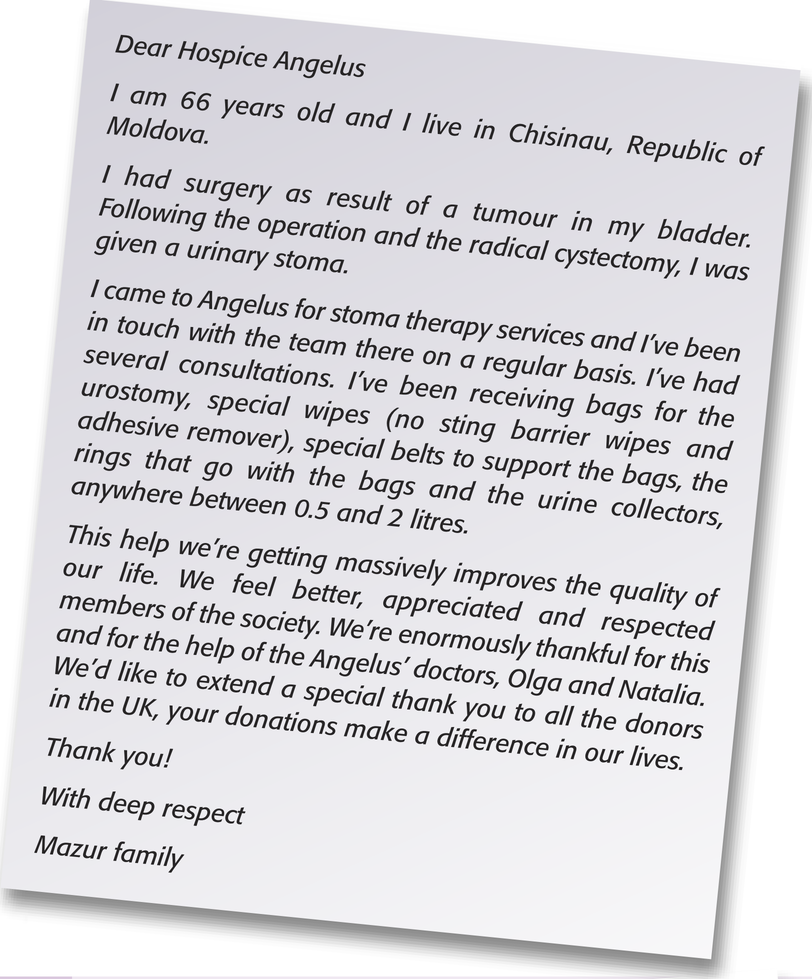
Why is Stoma Aid needed?

It is easy to forget how lucky we are in the UK: we have stoma care nurses to care for us, patient associations we can talk to, and stoma supplies are available on prescription and most people with a stoma are exempt from prescription charges.

However, many countries across the world don't have the things we take for granted. Many patients are forced to use tin cans, carrier bags, crisp packets and other improvised items as stoma bags as they cannot afford to buy supplies.

Stoma Aid makes a real difference to these people and has already started to change the lives of thousands of adults and children across the world.

Read this letter from one of the first patients to receive help through Stoma Aid:



Dear Hospice Angelus

I am 66 years old and I live in Chisinau, Republic of Moldova.

I had surgery as result of a tumour in my bladder. Following the operation and the radical cystectomy, I was given a urinary stoma.

I came to Angelus for stoma therapy services and I've been in touch with the team there on a regular basis. I've had several consultations. I've been receiving bags for the urostomy, special wipes (no sting barrier wipes and adhesive remover), special belts to support the bags, the rings that go with the bags and the urine collectors, anywhere between 0.5 and 2 litres.

This help we're getting massively improves the quality of our life. We feel better, appreciated and respected members of the society. We're enormously thankful for this and for the help of the Angelus' doctors, Olga and Natalia. We'd like to extend a special thank you to all the donors in the UK, your donations make a difference in our lives.

Thank you!

With deep respect

Mazur family

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

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

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.

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 our Enterprise House address that can be found on page 5.) **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 telephone **0844 879 4417** and arrange for your clothing collections to picked up at a convenient time and place for you.

Alternatively, you can 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: **http://icollectclothes.co.uk**

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

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. HB102

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.

Stoma Shield Ref. No. SS104

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

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

Ref. No. SS104

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

Junior Ostomy Support Helpline (JOSH)

Since launching at the end of 2014, the Junior Ostomy Support Helpline (JOSH) has provided vital support, assistance and advice to parents and carers of children with bowel and bladder dysfunctions.

The team of JOSH helpliners have a diverse background of experiences from which they can give practical advice and support. Whether our callers have questions about sleepovers or school trips – our helpliners are able to answer their questions and provide much–needed support.

Take a look behind the scenes at the JOSH helpline with some case studies since it first launched:

The Call:

A father called JOSH as he would be flying abroad with his young son for the first time. He wanted to know if there was any advice and reassurance regarding his and his son's journey.

What happened next?

A JOSH parent who had experience of travelling with a child with a stoma called him back and provided invaluable support. The helpliner advised the family to take extra equipment, check that the travel insurance provider knew about the stoma and that the cover was adequate. The father was also advised to make sure his son's bag was empty before the flight and reassured that travelling with a child would be okay.

The Call:

A mum rang JOSH as she was struggling to find support in her own area. She wanted to know if there were any support groups nearby that would be useful for a parent of a child with a stoma.

What happened next?

Although there were no support groups specifically for parents in her area, a JOSH helpliner called her back saying she knew of someone who belonged to **Breakaway** that held meetings nearby and passed on details of the group.

The Call:

A mum of a three year old boy called our helpline as she was struggling as a single parent to look after her child at home. Since he was first diagnosed with Hirschsprung's disease he has faced multiple problems and the mum's confidence had been severely affected.

What happened next?

A JOSH volunteer spent an hour on the telephone with the mum until she was feeling more confident in being able to look after her son. The volunteer reminded her that setbacks and challenges are normal but gave reassurance that she would be strong enough to deal with them.

Sometimes, speaking to someone who has gone through the same troubles as you can make a huge difference. Every trained JOSH volunteer is a parent of a child with a bowel or bladder diversion/dysfunction and they can provide unique advice and information.

Have you been affected by any of the issues mentioned or could you benefit from speaking to a fellow parent? Get in touch with JOSH today by calling the **Colostomy Association** helpline on **0800 328 4257** to arrange for a JOSH volunteer to call you back at a time that suits you.

The Call:

A concerned mother called JOSH as her daughter was set to undergo surgery for a stoma as a result of Ulcerative Colitis. She was worried about the future and what having a stoma would mean for her daughter.

What happened next?

She received a phone call back the next day from a JOSH parent for a general talk about her daughter's situation. The helpliner provided reassurance about the future and helped explain a little more about what it means for a child to live with a stoma. The JOSH volunteer sent out several booklets and literature by post for further advice, as well as signposting the mother to various other charities and organisations for more information. ■

Vanilla Blush

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Unisex Hernia Supportwear Vest

Level 3 Support - Same strength as a Hernia Belt

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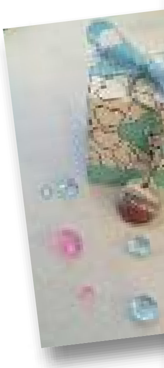
Post Surgery Brand of the Year

COMFORT COST - CONSCIOUSNESS COMPLIANCE

The breakaway Foundation

10 Celebrating 10 years The Breakaway Foundation



We've just held our 10th birthday gala dinner at the National Brewery Centre in Burton on Trent. We were delighted to be joined by 130 people to celebrate ten years of the Breakaway Foundation, including our special guests from the Colostomy Association (the very lovely Sarah Squire) IA, the Urostomy Association, the Association of Stoma Care Nurses and the Get Your Belly Out campaign. The venue looked fantastic, decked out with pink, blue and silver balloons. Duncan Wells, who many of you will know, gave us the great honour of coming along to be our Master of Ceremonies and Auctioneer.

The evening started with a glass of prosecco, and the opportunity to have a photo taken by professional photographer, Georgina Hine, who volunteered her services for free. We then had a delicious three course meal, with speeches from the Founder of Breakaway, Julie Bastin, our patron Mr Nour, Consultant Paediatric Surgeon at Leicester Royal Infirmary, Anne Demick, Chairman of IA, one of our professional volunteers Kevin Hayles, Specialist Stoma Care Nurse, and one of our Trustees Joshi Hicks, an ex Breakaway kid.

Then we were on to the main event, the auction and raffle. We had some great items to auction, including a signed Liverpool shirt from the current team, a signed football from the Chelsea team, and the training kit worn by Courtney Lawes, from the England Rugby 6 Nations team, plus a £200 John Lewis voucher donated by Salts.

Duncan then tried a trick that he'd been told about by Lord Archer (Jeffrey Archer) at a seminar a few years ago. He called Joshi up onto the stage and explained that Joshi represented a child whose parents couldn't afford the £185 it costs to attend a Breakaway weekend, and asked who would donate £20 to help send Joshi to a Breakaway weekend. Well hands shot up all over the room proffering £20 notes. Duncan then asked Pareet, another ex Breakaway kid up onto the stage and asked people to donate to help send Pareet to a weekend. There were so many people holding up money that we were running out of people to collect it! In the space of a few minutes Duncan had persuaded people to donate **£660!**

The raffle was a very popular affair, with lots of tickets sold, and some great prizes to be won, including some lovely malt whiskey, cupcakes made by one of the Breakaway mums who is a professional baker, as well as lots of vouchers for high street stores.

We'd like to thank everyone who came for making it such a great evening, and Convatec, Dansac, Pelican Healthcare, Salts, and Vanilla Blush for their support for the event.

Our 10th anniversary celebrations are continuing. We have our family fun day at Beaumanor, Leicestershire on 9 July, and our August family weekend at the end of August. It's onwards and upwards for the next ten years of the Breakaway Foundation!

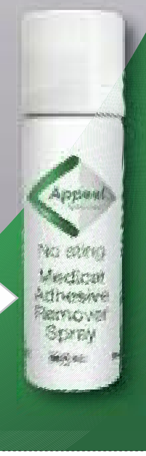
More information about Breakaway Foundation.

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


Appeel
No sting
Medical
Adhesive
Remover
Spray

Non Surgical Treatment of Parastomal Hernia

Simekuhle Ndlovu, Specialist Stoma Care Nurse, Royal Stoke University Hospital

There are over 100,000 people in the UK with a stoma, of which there are three types, colostomy, ileostomy and ileal conduit (urostomy).

Although many people have no problems with their stoma, research has shown that as many as 50% of people may develop a parastomal hernia. This may affect people in a number of ways including social isolation and restriction. A parastomal hernia occurs due to the surgical dissection of the muscle to bring the bowel through to the surface. This leads to a potential weakness at the stoma site which can result in a swelling or bulge around the stoma.

Why do parastomal hernias occur?

There are a few contributory factors including the position of the stoma within the rectus sheath (muscle), emergency surgery, age, weight, smoking and a history of a previous herniation. Early recognition is important to facilitate management of the hernia.

Hernia Prevention

Education is the key to helping to prevent parastomal herniation. Obviously some things such as siting of the stoma and surgical technique are the responsibility of the health care professionals but patients can also help themselves. Prior to planned surgery, patients are advised to reduce weight and stop smoking. After surgery they should support the abdomen, especially if coughing and avoid lifting for three months and take light exercise only for a three month period.

What problems might be caused by a hernia?

A hernia can cause pain and discomfort. Difficulty maintaining a seal with the skin can lead to leakage of the appliance and frequent removal of pouches can in turn cause excoriation (abrasion) of the peristomal skin. Obstruction of bowel action can also occur. These problems may all lead to a negative effect on body image and social isolation and restriction.

Coping with a hernia

Once a parastomal hernia is diagnosed treatments can be conservative (non surgical) or surgical. Conservatively the main treatment is reassurance and education. It can be argued that a change in lifestyle including stopping smoking, reducing weight if needed and light exercise to strengthen the abdominal muscles can help to reduce the potential for the hernia increasing in size. It can also help to wear an abdominal support garment. There are many companies who specialise in these garments and they can be made to measure, ensuring all patients have an abdominal support which provides the correct level of support in the correct position. A stoma care nurse can provide all the necessary information and can make a referral to one of these companies.

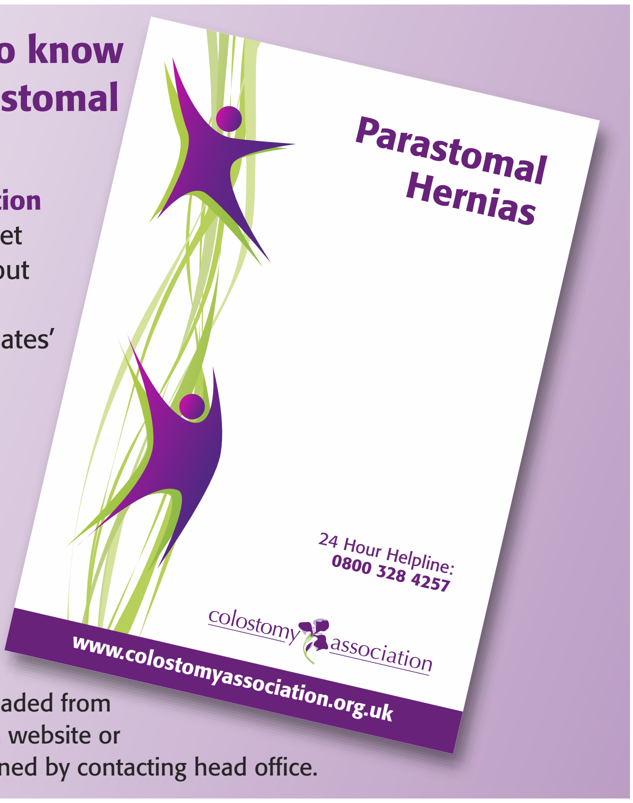
If, due to the shape of the hernia, pouch leakage is becoming a problem it is useful to get a review with a stoma care nurse who can suggest pouches with a more flexible or convex flange and also the use of additional products such as mouldable seals, belts and flange extenders.

Conclusion

Both health care professionals and patients can be instrumental in prevention and management of parastomal hernias through education and lifestyle changes which in turn can aid both physical and psychological problems associated with herniation. ■

Would you like to know more about parastomal hernias?

The **Colostomy Association** Parastomal Hernia booklet contains information about their prevention and management and ostomates' experiences of how they cope with a hernia.



This booklet can be downloaded from the **Colostomy Association** website or a printed copy can be obtained by contacting head office.

sponsored page

For over 60 years Coloplast has been striving to make life easier for people with intimate healthcare needs. Since 1954, when Nurse Elise Sorensen invented the ostomy bag as we know it today for her sister, Coloplast has been developing new products and services for ostomates across the world. This desire to improve the life of anybody living with a stoma continues today, and with it comes Coloplast's latest creation: the Core 4.

Core 4: An introduction to exercise with a stoma.

Exercise is a challenge even without a stoma. We are typically very good at coming up with reasons for not exercising and these reasons come in all shapes and sizes!

“I don't have time”

“I'm too tired”

“I'm too old”

“I don't know where to start”

The Core 4

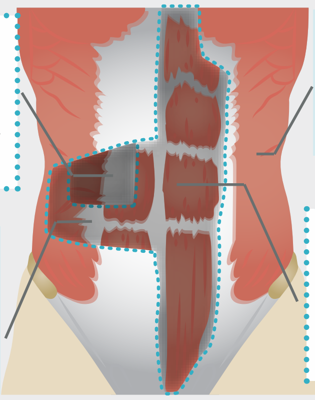
The Core 4 are four simple, easy to do exercises that are designed for everybody with a stoma. Each exercise can be carried out over a period of 5-10 minutes while lying down in bed, and could become part of your wake up/go to sleep routine.

The Core 4 focus on strengthening your abdominal muscles – the very muscles that hold your body together – and will have been impacted by your stoma surgery. Through strengthening these core muscles you will feel more able to do the things you want.

Developing the Core 4

The Core 4 has been developed in collaboration with a panel of experts including surgeons, physiotherapists, stoma care nurses, and ostomates. This panel of experts have been involved in developing the Core 4 and ensuring that these are the right exercises.

“Having confidence in your stoma gives you freedom to do whatever you wish. It therefore makes sense that taking care of your core muscles will set you on the road to a more active, healthy lifestyle. I would recommend the Core 4 as a safe programme for everyone with a stoma.” Ian Daniels. Consultant Colorectal Surgeon, Exeter.



Transverse abdominis
Located under the obliques, it is the deepest of the abdominal muscles and wraps around your spine for protection and stability.

External abdominal oblique
Located on the side and front of the abdomen.

Internal abdominal oblique
Located under the external obliques, running in the opposite direction.

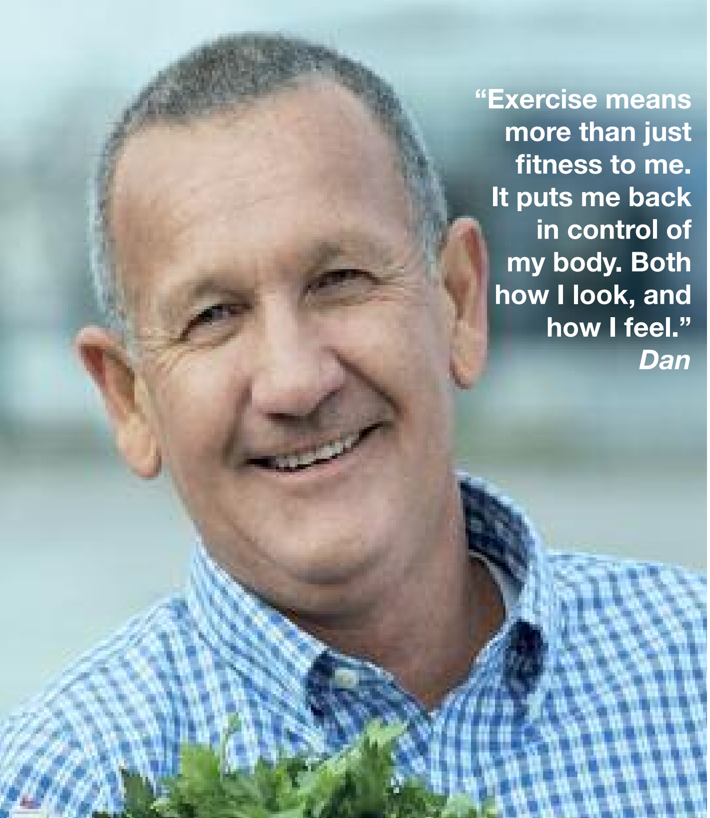
Rectus abdominis
Located along the front of the abdomen, this is the most well-known abdominal. Often referred to as the ‘six pack’.

This phased recovery programme will show you how to restore your core and rebuild your body, slowly and progressively.

If you have any concerns about your stoma, incision or whether or not you should do these exercises, then speak to your nurse or surgeon before starting.

Why should I choose the Core 4?

- Simple and manageable for all fitness levels
- Suitable for pre-op, post-op or lifetime ostomates
- Recommended by experts



“Exercise means more than just fitness to me. It puts me back in control of my body. Both how I look, and how I feel.”
Dan

Where do I find the Core 4?

Visit **www.coloplast.co.uk/care**, watch the video and request your free copy of the Core 4 brochure.

The Core 4 has been developed as part of the Coloplast Care programme.

For more information on living with a stoma, take the Ostomy Check at **www.coloplast.co.uk/ostomycheck**.

Accepting a New Lifestyle is not easy but it can become a carefree Norm!

As a new subscriber to the magazine I only wish I had joined your readers many years ago. I was too embarrassed to seek answers to many questions and problems while coping with the reality of an ileostomy and subsequently a colostomy. *Tidings* could have made my journey to what is now a normal lifestyle so much easier.

Like many other stories I have read in the magazine, my experience and goals are not unique. I admit it wasn't easy but if you are determined, nothing is impossible and you can reclaim your hopes and dreams, no matter what life throws at you, even the reality of a permanent unwelcome colostomy.

As an ex–military man, avid aviator and worldwide traveller, being told I needed a section of my colon removed was as welcome as being grounded on a sunny, summer's day. It was spring 2009 and I had planned a cruise to North America and Canada in the fast approaching summer. "No problem," replied my surgeon. "Although you are 70 you are healthy and strong. Pop in to the hospital for a spot of laparoscopic surgery and you'll be free to carry out your planned lifestyle within 10 days!"

Accepting his advice and the dire consequences of not, I submitted myself for the promised short and relatively painless procedure. Several hours after the operation, all appeared to have gone as planned and promised. However, all was not well. Over the next 10 days, tell–tale symptoms of possible internal problems were ignored or justified by my surgeon as recovery spasms and functional rehabilitation, whatever that was/is! I was discharged as forecast and although I tried to ignore my deteriorating health as part of a post–operative recovery, I was eventually forced to cry for help.

I called out my GP. She recommended that I drink more fluids and if this failed to call upon her again. A day later on feeling worse I called her again. Perplexed she summoned an ambulance and I arrived at A&E. I was examined, reassured and sent home. This happened again two days later and this time I saw a surgeon. He too reassured me that all was well and sent me home. On the third referral, I was eventually readmitted with a ruptured bowel, peritonitis and later septicaemia. My family sat around my bedside in intensive care as I 'coffin dodged' in and out of an induced coma for 11 days. Then, following six more trips to theatre and three months of fighting for survival in a hospital ward, a skeleton with an ileostomy and several non–healing tummy wounds was discharged out into the cruel world.

It was difficult to say the least. I now had a temporary ileostomy, three large openings that had to be dressed twice daily and any leaks from my bag had to be addressed before the wounds became contaminated. District nurses visited twice daily and I was encouraged to become as active as possible. I was coping, but with difficulty.

Winter was approaching and I hate the cold! I was becoming demoralised, more irritable and short tempered as time progressed. My patient wife, Philomena, being a retired district nurse, suggested we should escape to the sun and, to cries of: "are you both sure you want to attempt this?" from the medical profession, we flew to Madeira for a five week winter break.

With suitcases stuffed with dressings and stoma aids we drove 150 miles to the airport in a snow storm and, although I had to visit the aircraft toilet several times during the flight, we made it to our destination, accident free.

We settled into our hotel. Yes, it wasn't easy, but we were determined to beat the constant problems and win the day, every day. Accidents were frequent but usually while in our room or out of the public eye. On several occasions I was forced to leave the dining room/theatre seat on false alarms. We took every guided tour there was around the island and walked rather than bused everywhere. This is the life!

With increased activity, changing the dressings increased to four, sometimes five times a day. The ever demanding bag seemed to have a mind of its very own. Even with the glue–type sealant and extra sealing strips, it still found a gap to leak! However, we persevered and completed the five week holiday.

I continued to fly, even as a pilot in command of light aircraft, and took seven more cruises around the Med, to America, the Fiords, the Caribbean and even a long one to Singapore. All this with an ileostomy. 10 months later I had the reversal to form a colostomy. It was a great deal easier, but not problem free for the first year. I persevered and four years later I was introduced to the irrigation system. This was a life changer! Why had no one recommended this to me many years ago? I now flush every other day and the day between I have a care–free empty bag. Better than normal function I will dare to venture!

I hang the water reservoir above my shoulder and use two litres of tepid water. I find sitting increases the flow and less water is lost. It takes me 10 to 15 minutes to empty the container and I leave a minimum of 30 minutes seated before I venture from the bathroom. Another 30 minutes of keeping the sleeve attached, just to be sure, before I fit the pouch. Then it's 48 hours before I need to repeat the procedure.

I hope my story helps others who may at the moment be feeling that life will never be the same again, to take another look at how to win the battle of change and enjoy every second and every hour.

Kenneth Morris

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 am 76 and had a Hartmann's procedure to form a colostomy in 1990 due to bowel cancer. I was offered a reversal, but refused it as I had learnt to cope with my stoma and also had other medical problems so did not want to take the risk of another operation.*

In 2001 discharge from my rectum became a problem. I was told this was due to proctitis and I was given enemas which temporarily stopped the discharge. However last year it started again and I am concerned because the discharge is pinkish in colour and sometimes contains blood. Could this mean that my cancer has returned?

A: Patients who have a rectal stump left in place can have proctitis and they can pass blood and mucus from the rectal stump so it does not necessarily mean that your cancer has returned. However, I would ask to see the consultant again.

He can check the rectal stump via digitalisation with his finger and possibly even a look with a camera. This will get the answer for you and also give you an opportunity to discuss treatment for this discharge.

Some people continue with medication via enemas or suppositories and some people choose to have the rectal stump removed. This will, however, obviously depend on your health and the amount of problems it is causing as surgery does carry risks. I hope you get sorted out to your satisfaction.

Q: *Normally the area around my stoma is flat. However, occasionally it rises up in a bump. If this happens I remove the bag and press gently around the stoma. This causes a long sausage of faeces to emerge which I can catch in toilet paper and drop into the toilet. The area around the stoma then returns to its usual flat shape. Is this the same as a parastomal hernia?*

A: It may be the way the bowel has been brought to the surface and you can therefore press around it to expel the faeces which then reduces the impact of the bowel just below the surface being full.

A parastomal hernia is also a swelling around the stoma which can ache and protrude when you are standing or lifting things but would go flat on some occasions i.e. if you lie flat and relax the abdomen. If you are uncertain a check with your stoma care nurse would be useful as they may also be able to advise with regard to an abdominal support.

Q: *I would appreciate your thoughts on the points below and wonder if other ostomates share similar experiences.*

I have an ileostomy of long standing and find that artificial sweeteners can cause diarrhoea, especially sorbitol and its relations. I do not have a sweet tooth or take sugar in drinks. I find lots of groceries have these items in and taste very sweet and now take time to read labels. Recently I had to request that my antibiotics were liquid with a sugar–base, not sugar–free.

This brings me to the next point. On the television news concerns were *raised that crushing prescribed tablets for medical conditions could alter how they work in the body. Having an ileostomy I find that tablets of a certain type can turn up in the bag looking the same as they did at the start of their trip through the intestine that is left. So I chew mine first or crush them and add some yoghurt.*

On the news an example of cost was given, a prescription for blood pressure tablets cost £7, but in liquid form was £18. Should one talk to their doctor about this and are they aware of any problems.

A: You are correct in that some artificial sweeteners do cause a looser stool for many people including some ostomates. Therefore avoiding them is a good idea if they cause significant problems possibly leading to leakages from the pouch.

With regard to tablets being taken and appearing in the bag in the same form as when you swallowed them, I would suggest that if this does occur you need to talk to the GP or pharmacist about obtaining them in a different format.

I would not recommend chewing or crushing them as some tablets need to be absorbed in a certain part of the intestine and breaking them up in this way may affect the absorption and therefore the potency of the drug. This may then reduce the effectiveness of the medication which could have an impact on your health. I hope this helps.

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 notes 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:

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.**

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.

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

After reading your magazine and finding it very helpful and informative and knowing there are people with the same condition, some a lot worse than me, I felt tempted to put pen to paper.

My whole life and hobbies has been farming, tractors etc. Two years ago my world fell apart. After five years of numerous colonoscopies to remove polyps, I felt the need to be near the toilet all the time. When I started seeing blood I knew it was time to have further analysis. I went to Aberdeen Hospital on 6 January 2014 and saw my surgeon, Ms McKinley. I was diagnosed with abnormal bowel cells and was told I would need an irreversible colostomy.

As you can imagine it was devastating news for my family. I could not imagine life with a stoma and a bag…not me… never. I was allocated a stoma nurse, Alison, who covered every aspect of a colostomy operation, but my mind was in a whirl and not all of it sunk in. With great reluctance I went in to hospital for the operation on 22 January 2014 and woke up with various tubes and the dreaded bag. I couldn't really accept it, but it was mine forever.

I was allowed home 10 days later with a supply of bags and endless information on stoma care. My wife and family and stoma care nurse were brilliant with lots of patience. However, this had happened to me and I didn't want it, so I shut them out, didn't share my feelings. I felt so useless and sorry for myself. At bag changes I struggled to make sure it was on safely and correctly and was continually checking it. After four weeks and with all the tubes out I suddenly started feeling better. I could deal with my stoma, my world was coming back.

My life is a whole lot better for having a stoma, no seeking toilets, whenever we go out. I can change my bag in seconds. Holidays – no problem. I forget it's there and am very glad I had it done. I am enjoying life and back working, doing the job I have always done. I can't thank my family, my surgeon, Ms McKinley, and Alison, my stoma nurse, enough.

Yours Sincerely
T.H.

Editor: The stoma care department at Aberdeen Hospital was nominated for the **Colostomy Association's** *Purple Iris award in 2015 and received a highly commended certificate in recognition of their outstanding service to patients. If you would like to nominate the stoma care department at your local hospital for an award at our 50th Anniversary Celebrations in 2017 look out for the nomination form in the next edition of* Tidings *and tell us about how your stoma nurses helped you and why they deserve our award.*

Dear Editor

At long last I am putting pen to paper to thank you so much for sending me the *Tidings* magazine. It has been most helpful reading about how others cope with a permanent colostomy due to cancer surgery, especially as there doesn't seem to be a support group here.

My bowel problems began in the early 90s when I was living abroad but I didn't have a diagnosis until after I arrived home. My GP referred me to the hospital and after a barium enema I was told I had IBS.

In 2010 I received the bowel screening test kit and as usual sent it back with the required samples. I ended up repeating it twice more as they were finding blood every time, although it could not be seen with the naked eye. I was then sent for a colonoscopy but nothing showed up and I was given the all clear. Even when I started to see blood in my stool about six months down the line I didn't go back to the doctor as having had a colonoscopy I had a false sense of security. I thought it was just haemorrhoids as did my GP initially when I eventually went to see her.

The day I was diagnosed with cancer (6 March 2012) is unforgettable in that I went to hospital for a sigmoidoscopy and banding of haemorrhoids. The nurse practitioners were so good, but I began to have my suspicions when they said they

Readers' writes

wanted to take tissue samples. They eventually came back for a chat and said it wasn't haemorrhoids. I immediately said: "It's cancer isn't it." They agreed and we had a chat about scans, radiotherapy etc.

I had the usual five week chemo and radiotherapy and an APeR for an LRC (Low rectal carcinoma). I was admitted for surgery early August. The operation went well and I was in HDU for two days before spending 15 more days in the main ward due to hospital acquired pneumonia. Although I had no problems with the mechanics of changing the bag, I really hated having a stoma and especially the fact that it was not reversible. Although I've come to terms with it now, I still find it hard not having any control over when and where my stoma performs.

I, along with others, was horrified to see and read of the terrible waste of supplies. My prescription allows me three boxes (90 bags) per month but as my requirements vary from month to month depending on how my stoma is behaving, I just phone the surgery (repeat prescription line) when I need more. The prescription is sent to my local pharmacy which has a text message service to let me know when it is ready for collection – unfortunately they don't deliver.

My stoma nurse advised me to order more bags when I started the last box. This, I've discovered, isn't always long enough so now I tend to order soon after I start the second box. I also keep a box of drainables for when I get the 'runs' (or the day before a colonoscopy!) so I should not get caught short.

Yours sincerely
E.S.

Editor: All pharmacies or dispensing appliance contractors (DACs) choosing to dispense appliances in the normal course of their business are required to comply with a number of essential services. Home delivery, in an unmarked package is one of the services which must be offered. Also if you choose to use a local pharmacy to fill your script they must all provide supplementary items (disposal bags and disposable wipes) as part of the contract with the NHS. For more information on all of the services pharmacies must provide please refer to the Pharmaceutical Services Negotiating Committee website at: ***psnc.org.uk***

Dear Editor

Five years ago when I lived abroad in the Netherlands we drove back home to visit our family. As we had the car it was not difficult to make sure I had more appliances than usual to cover all eventualities for my urostomy and colostomy.

During our first stop at our eldest daughter's home on the Sunday I got food poisoning and my colostomy went into over–drive. The output was liquid and just constantly leaking under the convex baseplate; I went through six baseplates and bags in just one day, and started to panic about not having enough supplies for our trip.

Solution: on the Monday I phoned the manufactures of the bags I usually use and explained my problem. They agreed to send me some samples. Then I used my daughter's internet to find other manufacturing companies and phoned to ask them also to please send me some samples to my brother–in–law's address, which was our next stop.

My output slowed down on the third day and thanks to the samples sent by the manufacturers I had enough to get home, but the thought of being without supplies was a very scary one. I had taken three times as much as I would usually use but one instance of food poisoning was sufficient to go through all the spares.

Moral of the story: sometimes you have to look in a different direction to solve a problem. The manufacturers are always happy to send samples because they want you to use their products, and any bag will do in an emergency.

Kind Regards
Bobbie Minshull

Dear Editor

At the outpatient's clinic, having done an internal examination, the surgeon said: "Turn over. Sit up. You have cancer and you will have to wear a bag for the rest of your life." Just like that! I was under the impression that I had inflammation in my back passage. That was 30 years ago and Colin (née Colon) came into my life two weeks later.

When I read that *Tidings* was looking for stories about holidays from people with a colostomy I thought some readers might find our adventures "Caravanning with Colin" somewhat interesting and inspiring and consider following in our tyre–tracks. It was a couple of years after I had my stoma that my wife and I decided to take our trailer caravan to overwinter in the Algarve. We sailed from Plymouth on 11 December and after a 24–hour voyage on a sea as flat as a table and a good night's sleep in our cabin we arrived bright eyed and bushy tailed in Santander in northern Spain where we spent the first night.

The next day, the first stage of our journey was through the Cantabrian mountains and as we left the mountain pass to gain the plateau beyond the intermittent drizzle which had accompanied us gave way to clear skies and continuous sunshine until night fall, in fact it was 'Blue skies shining on me' for the rest of our journey to the Algarve. Our journey ended at Albufeira on the southern coast of Portugal on 15 December where we remained until the start of our homeward trek on 27 February.

During the whole trip Colin gave me no problem. In the caravan we had a Porta Potti with a flush mechanism (in a small enclosure), together with a hand basin with water from a portable plastic tank via a pump connected to the van's battery. These served us well in transit then at the campsite there was a communal toilet block.

They say all good things must come to an end and when ours did it was a real blow – a force nine gale on the return voyage from Santander to Plymouth – but while in the Portugal we had enjoyed 47 days of unbroken sunshine from dawn to dusk and rain on only three days.

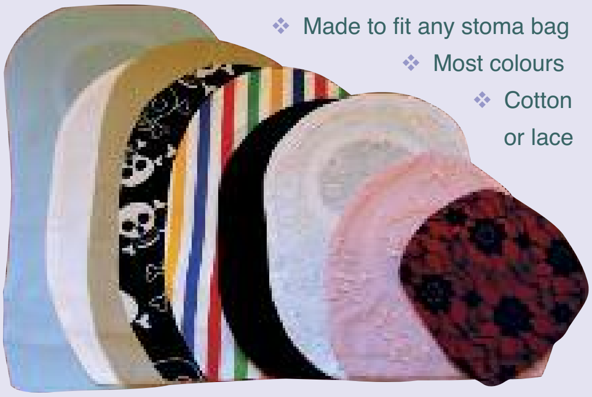
Colin is my best PAL and he came into my life in April 1986 and for me he has certainly Prolonged Active Life (as the label on the tin of this brand of dog meat proclaims). I'm now 87 years old.

Kind Regards
Frank

Dear Editor

The first time we went on holiday after my wife had her colostomy we went to a hotel we knew on the Isle of Wight. To avoid the embarrassment of having to dispose of the black bags she decided to use the Welland flushable pouch which

CONTINUED ON PAGE 59, COLUMN 1




SOMAerect
Penile Rehabilitation


SOMAerect Stf

Readers' writes

CONTINUED FROM PAGE 57, COLUMN 3

was the subject of some unforeseen hilarity between us.

The first time my wife changed her bag and went to flush the pouch it would not flush. She tried a number of times and in frustration asked me why it was not flushing. I looked at the toilet and realising the problem I said the problem was a smaller cistern. At this point I must mention that my wife is hard of hearing and I have a north country accent.

She replied: "small assistants" and I said: "yes smaller cisterns". This went on for some time with me not understanding why my wife couldn't recognise the problem and her wondering what small assistants had to do with anything. Eventually the penny dropped and I said "fork handles" and we both had a good laugh about it and so have numerous of our friends.

Regards
Peter Eltringham

Editor: Other readers may remember the Two Ronnie's sketch where Ronnie Corbett comes into the hardware shop to buy "four candles".

Difficulty with flushing may, however, be a problem of the past as the latest flushable pouch allows the flange to be detached so that only the liner and contents are flushed down the toilet.

Dear Editor

Regarding John Mason's letter/email in the spring issue of *Tidings* re travel insurance the following might be of interest. I had total pelvic exenteration surgery (removal of the bladder, parts of the bowel and the prostate) last February, for bowel cancer, and up until then my wife and I had travelled to The States a few times a year.

The horror stories about the cost of travel insurance, if it was offered, were a worry. After trying other specialist companies, without real success, we were recommended to try a company called Insurancewith. www.insurancewith.com

They were excellent! Given the complexity of my surgery, I was referred to the underwriters, and spoke to a lady called Miriam, who couldn't have been more helpful. The questions were thorough, but thoughtful, and it was my impression that she was trying to actually find suitable insurance, rather than be obstructive. Considering other quotes I had, their insurance was quite reasonable. We have since been on a mini trip to Bordeaux, and have booked a trip to Atlanta in June. I would certainly recommend this company.

David Cable

Editor: The cost of travel insurance can vary considerably. It is important to shop around and obtain several quotes and compare them on a like for like basis ie check the limits of cover and the level of excesses. It is important to inform your insurance company that you have a stoma as failure to do so can render the insurance policy invalid.

Dear Editor

I recently wrote to you about forming a support group in the area around the Royal Surrey County Hospital in Guildford. Well, together with the lovely stoma nurses from the hospital, we held a coffee morning in Milford Village Hall on Tuesday 19 April 2016.

We had over 60 attendees of which 32 were colostomates. I asked if they wanted to form a support group in the area and they all said yes. So we will now arrange the first meeting in about a month's time and invite them all along plus any others who could not make it or didn't know about the meeting.

We aim to cover West Surrey, East Hampshire and North Sussex, but people from other areas will also be made welcome. We would also like to extend the invitation to anyone awaiting a stoma operation so we can reassure them there is no need to be afraid and there is life after a stoma.

Best Wishes
Robin Young

Editor: If you are interested in going along to this support group call Robin on **01428 723255** *or e–mail* **robin.young11@btinternet.com**

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.

Cornwall Bowel Cancer Support Group

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

The group was formed in May 2013 by Candy Coombe and Clare Ferris, Colorectal Nurse Specialists, at Treliske Hospital in Truro. Due to the geography and poor transport infrastructure in Cornwall it was decided that an online group would be the best way to start. So on the 22 May 2013, the group opened a closed Facebook group, membership by invitation only through either Candy or Clare.

Since then the group has quickly grown and now has 150 members, who meet bi–monthly at the Probus Village Hall just outside Truro. The reasoning for the venue is that it is roughly in the middle of the county. The next three meetings will be on 6 August, 8 October and 3 December 2016.

The meetings normally run from 10:00am to 4:00pm and we encourage members to bring their relations along as well. Members serve refreshments during the day and we aim to make the meetings very informal by having jumble sales, entertainment and quizzes during the afternoon.

In May 2014 the group set up its own website which has proved to be very successful, having had over 12,000 hits since its formation. The site gives local and national information of interest to people with bowel cancer and their families. The site has also been involved in surveys carried out by universities.

L–R Group members: Stuart & Wendy Wilson and Pat & Phil Jennings presenting a cheque to Dame Floella Benjamin, Patron of Beating Bowel Cancer

As the group has grown so quickly, in December 2015 a full committee was put in place with a Chairman, Vice Chairman, Secretary, Treasurer and 14 committee members. All funds raised by the group are donated to charity; to date donations have been made to Beating Bowel Cancer (London Marathon), Hope for Tomorrow and the new Macmillan building project called The Cove at Treliske Hospital.

The group has two main aims for 2016: Firstly to get more information out to the general public proving that bowel cancer is not the embarrassing cancer. Secondly to let those people who have bowel cancer know that they are not alone and to encourage them to come and join the group.

This year will see further expansion of the group to include anyone living in the PL postcode area. With the help of Maria Lawson, Lead Colorectal Nurse, based at Derriford Hospital, people from Cornwall who have their treatment in Plymouth will now have the opportunity of joining the group.

Keith Anderson
Committee Member

For full information of the group or if you would like to join please check the following

www.cornwall–bowel–cancer–support–group.co.uk

If you would like to see your support group featured here, please telephone CA Head Office on: 0118 939 1537 or send your article and photos by post to: Editor, Colostomy Association, Enterprise House, 95 London Street, Reading RG1 4QA or if you prefer email your article and photos to: editor@colostomyassociation.org.uk

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Helping ostomates since 1967

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Thank you fort your suppor

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

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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

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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.

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

My Details: Title: Name: Surname:
Address:

Postcode:
Telephone (home): Mobile:
Email:
Optional Information: Date of Birth: Stoma Type: Colostomy ☐
Reason for your stoma: (Please tick) Ileostomy ☐
Year of operation: Urostomy ☐

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

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

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

☐ (Please tick.) **Yes** I would like to make **a single donation/gift** of ☐£15 ☐£20 ☐£25 ☐£50 or
other amount (please state) £ to the **Colostomy Association**

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

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

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

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

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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

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

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

National Support Organisations

Support organisations for people with stomas

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

Bladder and Bowel Foundation (B&BF)
www.bladderandbowelfoundation.org
Telephone 0845 345 0165

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 as well as to visit the Colostomy Association, IA and Urostomy Association stands.

These events are often organised by stoma care departments; invitations are sent out to all their patients and national patient associations are often asked to include information about the event in their magazines and on their websites. A range of manufacturers and suppliers will be invited to set up a stand to display their products and services.

Open Days can also be organised by manufacturers or suppliers. At manufacturers' Open Days only the company's own products will be on display and these events are often held when they have a new product they wish to promote. Suppliers may invite some manufacturers to share their Open Day.

An Open Day is, however, by no means all bags and support–wear. Tea and biscuits – sometimes even cream cakes or Danish pastries – are provided and there's time to seek advice from stoma care professionals and share experiences with other ostomates. There may be presentations about stoma related issues or talks about subjects of general interest. Occasionally, manufacturers hold Open Days at interesting venues ie football stadiums or stately homes and there is an opportunity for attendees to take a look round.

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.

Some forthcoming Open Days are listed below and a regularly updated list can be viewed on the **Colostomy Association** website.

Salts Healthcare
Maitlandfield House Hotel
24 Sidegate
Haddington EH41 4BZ
25 August 11am–2pm
Trevor.donald@salts.co.uk

Salts Healthcare
Apex Hotel
1 West Victoria Dock Road
Dundee DD1 3JP
2 September 11am–2pm
Trevor.donald@salts.co.uk

Stoma Care Open Day
Grimsby Town Hall
DN31 1HX
13 September 10am–3pm
(Drop–in session)
Stoma Care Team 01472–875345

St Marys Hospital Stoma & Continence Awareness Day
Thackray Museum
141 Beckett Street
Leeds LS9 7LN
22 September 9:15am–2:30pm

Shropshire B.O.T.s (Bums On Tums) Open Day
Memorial Hall, Smithfield Street,
Oswestry, SY11 2EG
13 October 10am–3pm
Tel: Irene Constable 01691 238357
ireneconstable@phonecoop.coop

Salts Healthcare
Kirkcaldy Beveridge Park Hotel
6 Abbotshall Road
Kirkcaldy
Fife KY2 5PQ
14 October 11am–2pm
Trevor.donald@salts.co.uk

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

Stoma support groups
in your county

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

Milton Keynes Stoma Association
Dee Stobie 0190 867 2918 or mksa@mail.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

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

Hertford Stoma Support Group
Ralda: 0199 253 5311

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

Tameside Ostomisticles
Paul Seavers on 0777 135 9046

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 0155 369 1370 / 768271 / 775698

Stars
Anne Browne: 0160 366 1751

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull: 0771 447 9320

Hexham Ostomy Group
Judith on 0796 792 7286

Northumberland Cancer Support
members@northumberlandcancersupportgroup.co.uk

Nottinghamshire

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

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

Nottingham QMC Stoma Support Group
Rosemary: 0115 9826 691 or Boyd: 07979 720 295

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

Somerset

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

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

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

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 Pat Jones 0165 678 6103

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 07810 292 024

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

Rest of the World

Austria Support
www.ilco.at or email: stomaselbsthilfeilco@tele2.at

Belgium Support
www.stoma.be or email: secretariaat@stoma.be

Bosnia and Herzegovina Support
www.ilco-stoma-rs.com or email: trivun.dragan@gmail.com

Bulgaria Support
email: kurtev.panaiot@gmail.com

Croatia Support
www.ilco.hr or email: info@ilco.hr

Czech Republic Support
www.ilco.cz or email: foreign@ilco.cz or info@ilco.cz

Denmark Support
www.copa.dk or email: sekretariatet@copa.dk

Egypt Support
email: nmelnikhaily@hotmail.com

Estonia Support
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Lithuania Support
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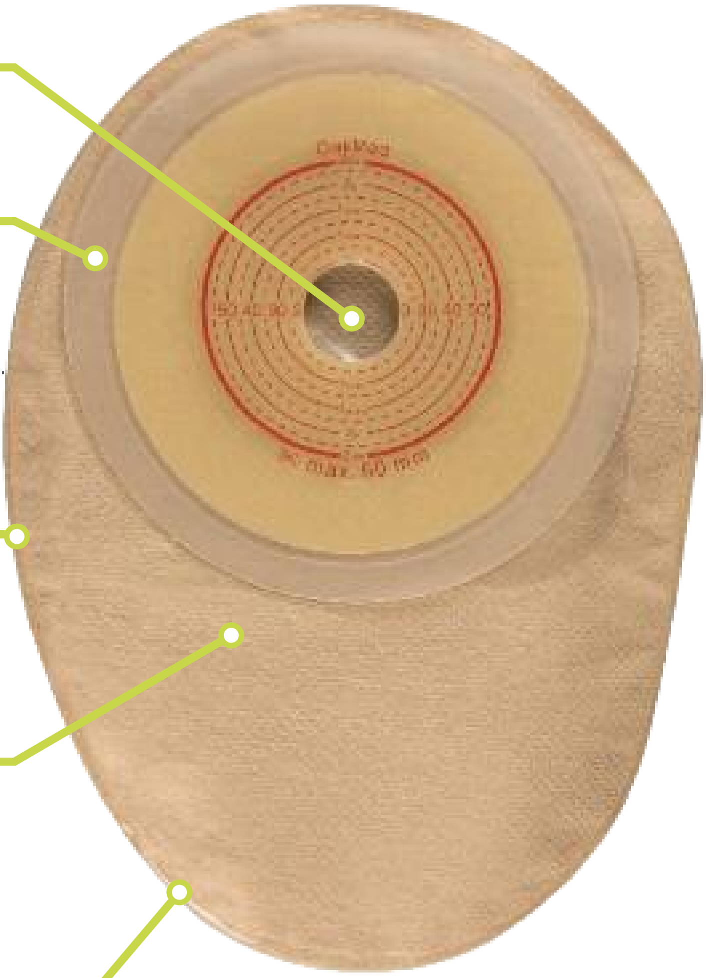
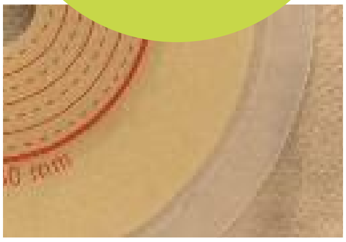


20mm starter hole

With pre-cut sizes available up to 60mm



Superb generous adhesive area

Reduces the need for flange extension products and gives extra security with larger stomas. Even when cut to 60mm, there is still 3cm of adhesive area left.

Split fabric front cover

On **all pouches**, for accurate positioning and easy observation.

New, thicker, superior soft fabric cover

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To fit body contours more closely.

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