Spring 2016 | Issue 41

colostomy association

Tidings

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

Special Feature: Holidays & Travel including

- **Hints & Tips for travellers**
- **Holiday Insurance**

Also

- **Parastomal hernias**
- **Two nurses with stomas**

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dear READERS

If you attended the Colostomy Association Open Day last July you will remember the excellent presentation on parastomal hernias by our president Ian Daniels FRCS.

Following on from this, we are delighted to be able to include in this issue of *Tidings* an article on this common complication of stoma surgery. As well as highlighting the need for more research into the prevention of parastomal hernias and the most effective way to surgically repair them, Mr Daniels emphasises that the decision to surgically repair a hernia isn't taken lightly. For those with mild or minor symptoms conservative management is often recommended. Therefore, in the next issue we plan to include an article from our stoma care nurse advisor Julie Rust and her colleague Simekuhle Ndlovu explaining how a different appliance or support garment can often reduce the problems associated with a hernia and improve quality of life.

Many years of training and experience equip stoma care nurses with the knowledge to advise and care for people with stomas. Many will, however, be the first to admit that they don't know what it feels like to live and cope every day with a stoma. In this issue we hear from two nurses who do. You may remember three years ago we included Molly's story in *Tidings* about how she was diagnosed with Crohn's disease at the age of 13 and subsequently had a colostomy; she now tells us how she recently qualified as paediatric nurse. Alison Horner on the other hand writes about her career in nursing at St Mark's and on colorectal wards in other hospitals. She says: "Much of what I have been through has allowed me to truly empathise with my patients." Her story ends as she flies off on holiday for the first time with a stoma.

Holidays and travel are the special topic for this spring issue of *Tidings.* Hopefully this will persuade those of you that have not stayed away from home since your stoma surgery that travel with a stoma is not only possible but can be as enjoyable as holidays in the past. Even though it is now almost 25 years ago I can still remember how apprehensive I felt before I went to stay away for the first time after my stoma surgery. The answer for me was to take a short break close to home to begin with then venture further afield as my confidence increased.

Planning ahead is also important. Peter Martin answers questions about travel insurance that we frequently receive on the helpline from ostomates preparing to travel abroad. Sarah Squire passes on hints and tips collected from **Colostomy Association** volunteers, *Tidings* readers and Facebook members. This includes tips for irrigators on her regular irrigation page as well advice on going through airport security and reassurance for those concerned about flying for the first time after their stoma surgery. A reader writes about the plans she made before her first cruise and concludes that cruising is an ideal way for an ostomate to see the world. Maybe, however, you prefer to stay in the UK; David Ford, one of **Colostomy Association's** volunteers in Wales, describes some of the interesting places in Britain he has visited in his campervan.

So don't let having a stoma stop you getting away to destinations either in this country or abroad. Just pack your bags and off you go…and when you get back do write and let other readers know how you got on.

Have a great time

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

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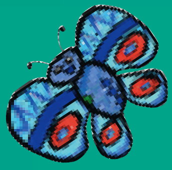

How to get in touch with the Colostomy Association

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

Simply contact us by post:
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By telephone:
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Stoma care queries only:
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inside this issue

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Updates

From Healthcare Professionals

Living with a Stoma

Real Lives

Focus on... Holidays & Travel

8 page feature

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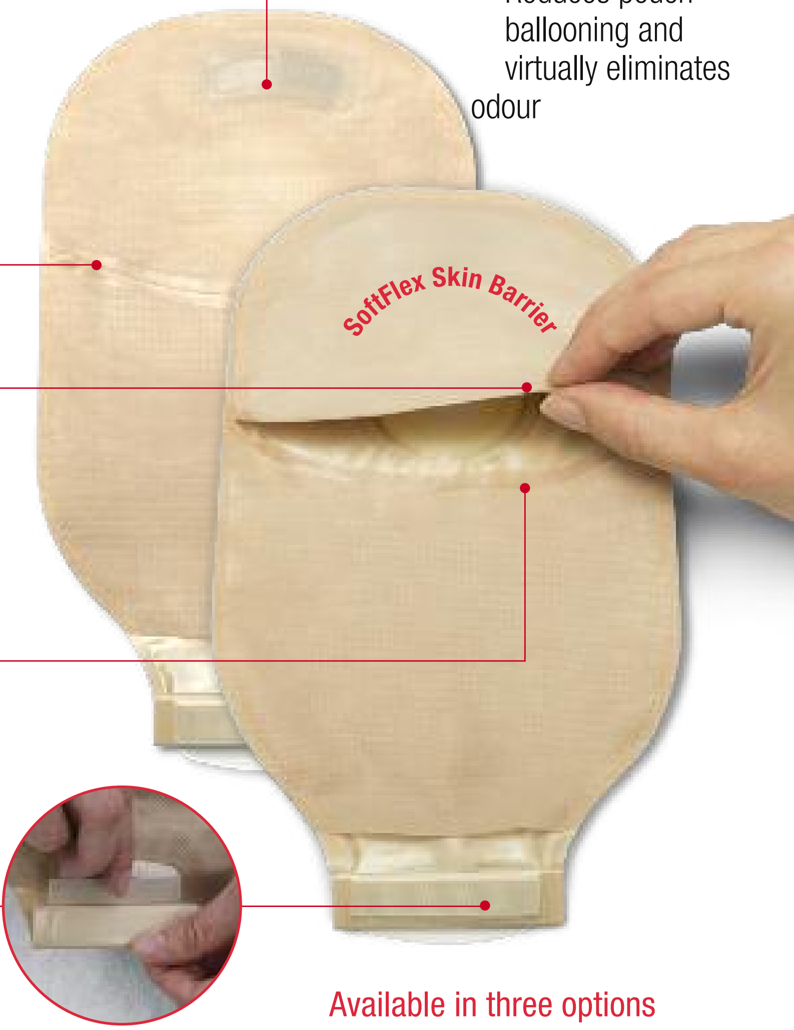

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From Patient to Nurse

It is tough to choose the right starting point for this story of 'my life with a stoma'. I suppose I should rewind the clock and begin from when I was diagnosed with Crohn's Disease in 2004.

At age 12, I was as thin–as–a–stick, seriously unwell and malnourished. Therefore it comes as no surprise that I was admitted to hospital for 8 weeks (my first of many admissions). At this stage in my life I was new to understanding Crohn's disease. I was also battling with M.E. – although looking back, I believe M.E. had been masking a lot of the symptoms of Crohn's.

I missed 4 years of school and no–one believed I would return to my original year–group once I was well enough to attend classes again aged 15. But I proved them wrong and I sat my GCSEs with my class; sure I took a reduced number but who needs 12 GCSEs these days?

However it was during this time that another problem emerged. I was experiencing what can only be described as 'leaking'. My Crohn's was under control but the damage it had done to my colon, rectum and anus left scarring which caused these life–restricting and embarrassing symptoms such as leaking and a constant urge to go to the loo.

Looking back I have no idea how I completed my 'A' levels. I would dash from the car to the loo before class and then tense my whole body through lectures in the hope I wouldn't leak, before scuttling home again.

This had to stop. After various hospital visits and exploratory procedures I returned to see the Professor to see what else he would try. Out of nowhere he said that realistically the next step was to form a stoma. He explained what a stoma was with little empathy but I think I zoned out – I was so shocked by this suggestion that I was silent the whole way home. Having a stoma had never crossed my mind.

We got a second opinion. This consultant was amazing and explained the options. He explained that having a stoma was possibly the best idea for me.

In August 2011, I said 'yes' to having a permanent colostomy. Walking out of the hospital after making that decision, I felt terrified but determined that it was time to live the life I deserved.

I had a meeting with the wonderful stoma nurse team before the operation to be marked up and to see the bags I would have to use. Afterwards I burst into tears. I think that I had been living in a bit of a naïve bubble about life with a stoma and hadn't realised how major the surgery was going to be.

In October 2011, at the age of 19 my stoma was formed. Humour definitely helped me through tough times after the operation – it is a long recovery process. I named my stoma Neville! No idea where the name came from but it helped so much and now all my family and friends refer to my stoma as Neville.

I chose to irrigate which has been brilliant in giving me a little bit more control over when Neville will be 'active' – although he still rebels and does his own thing at times! I also decorate my bags to brighten–up a bag change – plus it looks really colourful when I'm wearing a bikini.

I am now 23. A lot has happened in the four years since I had Neville. I had to have a further bowel resection last year due to numerous bowel obstructions – for four months I was on a liquid–only diet. I was in my final year at University and I had to put my degree on hold for several months recovery time. I had to continue my degree whilst all my friends had graduated. It was tough and I really didn't think I would finish it. But in December 2015 I completed my final placement and I am now a nurse! Due to the nature of Crohn's I know it can reappear at any time but all I can hope is that it allows me some good health for the start of my career.

Neville is with me for life. Luckily I love him (most days). I do have tough days with him though where he 'plays up' but overall he has changed my life for the better and given me a chance to have a future. I would never have been able to go to University without him. I would never have dreamt that I would qualify as a Paediatric Nurse without him. I would not have participated in a sky–dive without him. I would not have climbed Mount Snowdon without him. I could not have stood or walked any distance before I had him. Just the simple act of taking my dog for a walk is a real privilege.

Quite a lot has happened in my 23 years! Who knows what adventures Neville and I will embark on in the future? ■

Get ready for COLOSTOMY DAY 2016

The **Colostomy Association** is calling on ostomates, carers, family members, businesses and the general public to help us fight the poo taboo this October by getting involved with Colostomy Day 2016.

Colostomy Day is a national awareness day which takes place on the first Saturday of each October to help tackle some of the issues faced by people in the UK who live with a stoma.

The theme for Colostomy Day 2016 is Fight the Poo Taboo and we'd like lots of people to get involved. It is estimated that almost 1 in every 500 people in the UK currently live with a stoma but it still remains a little–understood condition to the general public.

To help tackle public perceptions of having a stoma we are asking ostomates across the UK to speak out or go silent for Colostomy Day.

MAKE SOME NOISE

Grab people's attention by making as much noise as possible about life with a stoma on Colostomy Day. Help tackle the poo taboo by speaking out or being as loud as you can.

Possible activities include wearing fancy dress or loud clothing, shouting out on social media or making some noise in public.

STAY SILENT

Alternatively, perhaps you could go silent for the day to highlight the difficulty many ostomates face talking about their condition. You could do a sponsored silence, hold a silent disco or even go silent on social media for the day with an explanation about why you're doing this.

The **Colostomy Association** is committed to improving public perceptions about people living with a stoma. Colostomy Day is a fantastic way not only to raise awareness of the issues faced by people living with a stoma but to have some fun as well.

Speaking about Colostomy Day, the **Colostomy Association's** Marketing Communications Officer – Niall Norbury – said: "In recent years we have started to see a positive change in the attitudes towards people living with a stoma but we still have a long way to go.

"Colostomy Day is a great opportunity for the stoma community to challenge negative perceptions and attitudes. We're calling on patients, carers, family members, manufacturers, businesses and other charities to get involved and fight the poo taboo." ■

If you'd like to get involved with Colostomy Day 2016 then please request a free inspirational pack giving more information about how to make this a special event via **0118 939 1537** or **cass@colostomyassociation.org.uk**

Please help us make this year's Colostomy Day even bigger and better than the last and look out for further details in the July edition of *Tidings*.

Come on everyone, let's go for it and get 1 October 2016 in your diary!

Neil Smart PhD, FRCS(Ed)
Consultant Surgeon
& Senior Lecturer
University of Exeter

Hernias, Hernias, Hernias and Hernia Support

Ian Daniels FRCS
Consultant Surgeon,
Royal Devon & Exeter Hospital
& Exeter Medical Ltd

The issue of parastomal hernias has gained recent focus in the minds of the professions treating abdomino–pelvic disease. Whilst this article is likely to be read mainly by colostomates, much of what we discuss is as applicable to urostomates and ileostomates.

One of the current *health hot topics* and which numerous organisations are focusing on is the *Survivorship Agenda.* This was originally coined by Macmillan Cancer Foundation to address the issues of patients who had survived (beyond) their disease or were living with their disease. Much of the focus is on a patients' quality of life, traditionally something not formally assessed as compared to quantity of life, ie how long a patient has survived and for which outcome is measured.

Many clinicians, nurses and patients have questioned this focus on quality of life, and much of the (cancer) follow up is focused on being disease–free, not symptom free. For many, the reassurance that their cancer is behind them is tempered by the feeling of having to live with the consequences of the disease; a stoma, a hernia, reduced quality of life, limitations on work, etc, especially as the risks of recurrence lessen with time. Indeed many patients, particularly those with a 'benign disease' such as diverticulitis, are only followed up in the early months following their surgery by a surgeon, much of the remainder of their life it is by their GP, stoma nurses where available, or *just getting on with it.*

For the ostomate there are a multitude of issues that may impinge on their quality of life based around the interaction of the appliance and the surface of the body to which it is applied. We do not need to remind ostomates of the concerns of pancaking, appliance security, leakage, etc, but the factors that impact on this are multifactorial.

We talk about parastomal hernias, and we see bulges on the abdominal wall. But what do we mean? And how do we assess it? To highlight many of the issues we'll use famous quotes:

> "The better is the enemy of the good"
> *Professor Bill Heald, OBE, MChir, FRCS, Surgeon Basingstoke*

As surgeons, the temptation when assessing patents is that we **can** make them better, but to contrast this if someone is already good, lives with their prominent stoma, but functions well, perhaps we can do better, but we have enormous potential to do worse! But is it really a hernia, or perhaps more importantly, what is a hernia?

Parastomal hernias are the most frequently occurring problem seen following the formation of a stoma. It can affect patients' body image as well as their self–confidence. They are more commonly seen following colostomies in comparison to ileostomies and this can be due to a number of reasons. Many ileostomies are temporary and have a shorter duration of follow up compared to colostomies. We must recognise that unlike other types of incisional hernia where there is a weakness in the wall where two edges have been brought together, a stoma creates a hole in the abdominal wall that is permanent. The *hole* in the abdominal wall remains and has the pressure of not only the other organs in the abdomen, but also the continuous contracting and relaxing of the abdominal wall muscles around it.

Causes

Different factors can affect the risk of developing a parastomal hernia. Patient factors include advanced age, wound infection and obesity. The older we get, the thinner and weaker the abdominal wall muscles are and therefore hindered in providing adequate support for the stoma. Conditions that increase the pressure in the abdomen such as persistent coughing (as seen in patients with Chronic Obstructive Pulmonary Disease – COPD), or jobs involving heavy lifting can also increase the risk of developing a parastomal hernia. Other factors such as nutritional status, the use of steroids or other medication that suppress the immune system can influence how well tissues heal after the formation of a stoma. However, much of the risk is probably in our own genetics…some people are more stretchy than others!

Technical factors that may increase the risk of parastomal hernia formation include whether the stomas was formed as an emergency, whether it was done open or via key–hole surgery or whether ostomy formation was part of another procedure. Keyhole surgery is reported to have a lower risk of causing a parastomal hernia compared to open surgery, however, long term follow up is awaited. Surgical technique can influence parastomal hernia occurrence, as can the diameter of the hole in the abdominal wall.

CONTINUED ON PAGE 11, COLUMN 1

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CONTINUED FROM PAGE 9, COLUMN 3

Formation of stomas

The technique of creating a stoma is one poorly taught, there is little standardisation of technique and the use of prophylactic mesh is currently the subject of much debate.

Problems with parastomal hernias

A parastomal hernia can present with a bulge around the stoma site and can also cause pain, abdominal discomfort, back pain and intermittent cramping. More serious complications include a bowel obstruction and/or strangulation of the hernia, where the bowel gets stuck in the hernia and can't go back in. This can be potentially life–threatening and requires immediate medical attention. For people that only have mild or minor symptoms, we recommend conservative management in the form of hernia belts or appliances. This is mainly to improve patient comfort and ostomy functioning. More severe symptoms might indicate the need for a surgical repair, although this decision isn't taken lightly as there is a high risk of hernia recurrence. It is generally reserved for people who have chronic symptoms that impact on quality of life. However, just like every other form of hernia, appropriate assessment, lifestyle modifications and occasionally abdominal recontouring should be considered prior to surgery. I suspect few patients undergo a CT scan, face–down with their stoma in a donut to truly assess the hernia, and little consideration is given to the dynamics of the abdominal wall and stoma placement.

Surgery

> "A fool with a tool, is still a fool"
>
> *Brendan Moran, Surgeon Basingstoke*

Like all operations where a large number of procedures have been described, this usually means no one knows what's best! It is easy to think that fancy materials and keyhole surgery are the panacea for all ails, yet an operation poorly performed, for the wrong indication and lack of appreciation of the potential complication can lead to later complications more difficult to manage, an unhappy patient and a more complex situation. Sometimes though, the stoma causes multiple problems, but where there are additional hernias, skin changes and a large aperture…then surgeons reconstruct everything. Known as the Buy One Get One Free (BOGOF) see *Figure 2.* To manage a problem like this, it's about managing the whole abdomen…and the whole patient.

Stoma care

> "Do no harm"
>
> *Hippocratic Oath*

When faced with a patient with a hernia or other complication, surgery should be the last thing on the mind of the surgeon, a combined review with a stoma nurse, a new appliance, a change of support etc, is the first port of call to assess whether this can improve the interaction. Similarly an understanding of the symptoms, for example, the night working stoma, obstructive symptoms etc can aid in the management…ask the right questions! Patients that do not have an indication for surgical repair can be managed with a stoma belt, which is designed to provide stability around the stoma site and to minimise the visible 'bulge'. The main aim of a stoma belt is to help fix the stoma appliance in place and to reduce the shearing and therefore, reduce complications such as leaking. It does not reduce the hernia. An appropriately sized stoma belt (by an stoma nurse) will result in very few complications.

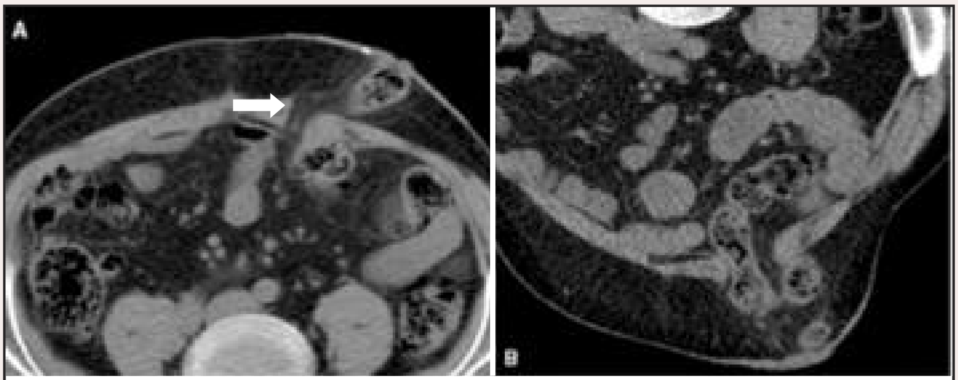


Figure 1: This diagram shows the difference in scanning a patient on their back (figure A) compared to their tummy (figure B) to demonstrate the hernia. The tummy is relaxed in one and then the hernia becomes apparent when prone.

> "An ounce of prevention is worth a pound of cure"
>
> *Benjamin Franklin, USA*

Current research – mesh etc

A mesh can be placed at the time of ostomy construction and this has been associated with a lower rate of parastomal hernia formation. Much of the recent research is about the use of mesh placement, type of mesh to prevent, or reduce the incidence of complications and hernia formation. Similarly as we have seen with managing complex abdominal wall hernias, lifestyle modifications can go a long way to improving outcome following surgery…In Exeter, "Smokers are Terrorists" and we won't offer hernia surgery, whilst patients still smoke…and there is a mountain of data to prove why not!!!

Quality of Life

However, when it comes down to it, it is about quality of life. What do we mean by that for an ostomate and how do we measure it? Well the simple answer is that we don't currently measure whether a person is living successfully and independently after surgery. But there is hope on the horizon. The Exeter Surgical Health Services Research Unit (HESRU) and Bristol Clinical Trials unit have been awarded a grant of over £1m by the National Institute of Health Research to develop these tools and to look at every aspect from making stomas, to meshes, to measuring problems from them. There is much to do…and your help is needed. Read more about my involvement with HESRU at **www.hesru.org**

Ian Daniels FRCS

Figure 2: The BOGOF Procedure.
In this example trying to treat the stomal hernia is only part of the process. Weight loss, increased fitness, lifestyle changes, repairing all the hernias together, and then a "tummy tuck" allow the creation of a new stoma on a flat surface.
Giving someone a renewed outlook on life…
..but this is not a simple fix!

From Nu
to Pati

Alison, a senior staff nurse at St Mark's Hospital, London in 1988

My first encounter with a stoma was aged 15 when my Mum had emergency surgery.

Then in 2011 my Dad, aged 75, suffered a perforated bowel from diverticulitis and ended up with a temporary ileostomy. Although many years have passed between my Mum and Dad's surgeries, I've been up close and personal as a family member. Definitely a family with dodgy guts!

When I began my nurse training in 1983 I took what I had learnt from my Mum's experience with me to help my patients. During my training at St Bartholomew's Hospital in London I was sent to St Mark's Hospital for an eight week theatre placement. Locally, the taxi driver's referred to it as the 'bum hospital'! As students we were actively encouraged to 'scrub' and start taking cases under supervision. The surgeons were brilliant, teaching and supporting us. As soon as I qualified I went back to work at St Mark's, first as a staff nurse on one of the wards, then into theatres again. I then returned to work on the wards as a senior staff nurse and I saw all sorts of different reactions from patients having a stoma, some of which stay with me today.

Eight years later I was a young mum living in Portsmouth. I returned to working in colo–rectal theatres and was surprised how much I remembered from my St Mark's days! Eventually I went to work in the Intensive Care Unit and would occasionally look after bowel surgery patients there too.

At some stage in our lives all those who work in the health environment will find themselves on the receiving, rather than giving, end. No one could have prepared me for what happened when I became ill and there were times when it felt quite surreal. I found, with my relatively in–depth knowledge, that it just increased my fears to a whole other level. There were times when I wished I didn't know so much, times when I wished I could switch my 'working' brain off. I don't know what the doctors and nurses expected, if anything, from me, but I was determined to be a 'good' patient and help myself as much as possible. Perhaps, in hindsight, I took this too far and turned down offers of help when I should have just said "yes please"!

I became ill in July 2014 developing a familiar tummy pain. The previous year I had been diagnosed and investigated for diverticulitis. Surgery had been discussed but it was felt, at least for the time being, that it could be managed medically. This turned out to be my fifth attack in one year and went to a whole different level. By lunch time the next day I was seriously unwell. I had never felt so ill, I had a rigor, was vomiting and feverish and the pain in my tummy was horrendous. Quite frankly I was terrified. It was like there was a mini version of me sitting on each shoulder. One was Patient Alison, the other Nurse Alison. Patient Alison was saying: "I feel awful, scared, so much pain, something must be really wrong". Nurse Alison was evaluating all the signs and symptoms and coming up with a diagnosis! I understood only too well the results of all the examinations and observations when I was admitted into hospital by the GP.

I was treated medically again, IV antibiotics and fluids and had CT and ultrasound scans. I managed to persuade the consultant to let me go home a few days later so that I could attend my son's graduation in Leeds. Surgery was now discussed as this episode was a 'game changer' and it was agreed to admit me in four to six weeks' time. I knew surgery would involve a stoma of some sort and tried to start mentally preparing myself.

Despite taking antibiotics I was spiking fevers and I felt so unwell. I was hardly

urse ent

Alison three months after her surgery

eating anything as it just made my abdominal pain worse, and I was not passing anything but mucus from my bottom. The weight started to fall off me. Even though I was admitted as an emergency I had to wait four days for my operation. I tried to rationalise why someone else would need theatre ahead of me – perhaps there had been a major accident. My surgeon came to apologise for not being able to do the surgery that day and said they would do their best to treat me the next day. I started to think I was going to die before they got to me.

One lady in my ward beckoned me over and asked me what I was having done. In an instant she had whipped up her nightie and was showing me her urostomy and large, long–ago healed laparotomy scar. "See dear that's all it is, nothing to be frightened of." I thanked her for her kindness and went back to my bed.

The stoma nurse had come to mark me up the day before surgery and asked me to explain to her what I was having done to check my understanding. After a few words she stopped me and said: "what do you do"? I told her and discussed my fears. As I lay in the bath, careful not to wash off those black spots, one each side of my tummy, I knew I would never be the same again.

I had gone into great detail with my surgeon about the procedure before signing the consent form, even requesting a certain type of wound closure! I was beyond terrified knowing what my body was about to go through but knew it was that or die. My surgeon reassured me that there was a good team to take care of me, and I thought "yes he's right. I was part of that team once". The whole situation remained a bit surreal and I dearly wished it wasn't happening to me. The outcome in terms of type of stoma and procedure was uncertain as it was not crystal clear what the situation would be until they saw inside me.

After the operation I spent two days in Surgical High Care and was then transferred to the ward. I tried to do all the things I knew I should do like taking regular deep breaths and moving my legs. Getting out of bed some 48 hours after I had gone to theatre was one of the hardest things I've ever had to do. My legs were like jelly and my wound felt so painful and tight, I sobbed tears as I was helped into a chair. Yet, extraordinarily, I gave career advice to a student who wanted to aspire to what I do now! My working brain just never switched off!

My surgeon (the amazing Mr David Pares) told me that they had been unable to join me up as everything was so swollen, and that they had to remove some of my rectum as well. He said I was one of his 'most suffering patients' and remarked that I must have been in so much pain. I was very emotional and gripped onto his hand and thanked him for saving my life. He responded by saying: "You are welcome", just as I had done to relatives when I worked in Intensive Care. What struck me then, and still now, is the intensity of the gratitude I felt towards Mr Pares. For us, we really are just doing our job and glad to be able to do it and make a difference, but it is quite another thing when experienced from the other side.

Changing my colostomy pouch for the first time was utterly exhausting; I found it difficult to concentrate and my hands were shaking. I had little stamina due to the prolonged sepsis I'd suffered before surgery and I was quite anaemic. I tried to be the 'good' patient but I wanted to tell the stoma nurse I'd had enough and couldn't she see that?

The lack of privacy in a ward is grim. There is no real confidentiality as we all hear about each other's situation through the

CONTINUED ON PAGE 15, COLUMN 1

From Nurse to Patient

CONTINUED FROM PAGE 13, COLUMN 3

curtains; the trouble for me was that it all meant something. Determined to get home, I was discharged four and a half days after my surgery. Looking back I don't know how I did it. I struggled so badly to change the stoma pouch and admonished myself. I'd done it for many patients yet I couldn't manage it for myself. My daughter sat patiently with me and encouraged me as I gradually got the hang of it.

Then I got a wound abscess which burst and terrified the life out of me. I thought my whole wound was breaking down, but of course it wasn't. Nature had done what it does best and drained all the pus from the abscess. However, because the drainage hole was so tiny it kept healing over and the abscess reformed each time. It took me three weeks of visiting GPs to finally get what I needed – the wound opened up a bit to allow it to be packed. I know the system yet I felt I had to battle for everything. How on earth do others get on? I took charge of doing the dressing myself to keep some control of my life which was becoming one long round of doctor's appointments, hospital appointments and prescriptions.

I regained my strength and slowly but surely built up my activity by walking and walking and walking some more! After three months I returned to my job, as a nurse practitioner in a GP surgery, on a phased return and was completely exhausted. By nature I am a workaholic and found it hard to pace myself, but there was a part of me that wanted to return to 'normal' as soon as possible, and that meant work. Then one day, quite recently, I realised that I had not healed psychologically. I needed some time out to accept what had happened to me, including the decision I'd made to keep 'Sid', my stoma, as the outcome for reversal is too uncertain for me. On Christmas Eve I worked my last day whilst I decide what to do next.

Much of what I have been through has allowed me to truly empathise with my patients, and with a few I have shared my story in an effort to help them. I don't broadcast what has happened to me but I am happy to talk about it if asked. Regarding 'Sid' I often get told "well you'd never know" like having a stoma would be blatantly obvious! I have tried not to let having a stoma prevent me from doing anything I want to do. Since my op I have returned to running, got on my bike, and I flew to Australia in November, though I have to admit trying to empty Sid's bag at 38,000 feet in turbulence was a little stressful!

Alison Horner

Photo ID Card

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

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

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

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

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

Please allow 10-14 days for delivery – thank you

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

To obtain a **key or a photo identity card** please **complete the form and declaration.** Make your **cheque payable** to the **CA Ltd.** Return all required items to: **Enterprise House,**
95 London Street,
Reading, Berkshire RG1 4QA

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

National Key Scheme - Key and photo ID card purchase

Title:

Name:

Address:

Postcode:

Tel:

Email:

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

Please **tick** as appropriate:

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

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

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

Signature of self or carer:

Date: / /2016

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

STOMA HERO.

VOTE FOR YOUR 2016 STOMAHERO.

ConvaTec is delighted to announce that the Stomahero Award is now open for nominations. We know how important your Stoma Nurse is to you and this is your opportunity to say a big thank you!

ConvaTec is there for every person with a stoma throughout his or her entire journey and we recognise the crucial role of the Stoma Nurse throughout that process. The Stomahero Award has been developed to acknowledge the patient care and support delivered by Stoma Nurses across the country and to give patients the opportunity to nominate and say a huge thank you to their nurse for the continued support before, during and after surgery.

The Stomahero Award Nominations are judged by three patient associations, the Ileostomy Association, Colostomy Association, Urostomy Association, together with an Amcare™ Group Stoma Nurse and an independent Stoma Nurse. Patients are invited to submit nominations via post and emails, all Stoma Nurses with more than one nomination are shortlisted to the judging panel.

The winner receives a £3,000 educational grant which can be redeemed against a stoma education course or an educational conference event, to help support the development of their stoma department and their own personal career development.

@ConvaTec_UKI /ConvaTecUKI @ConvaTecUKI

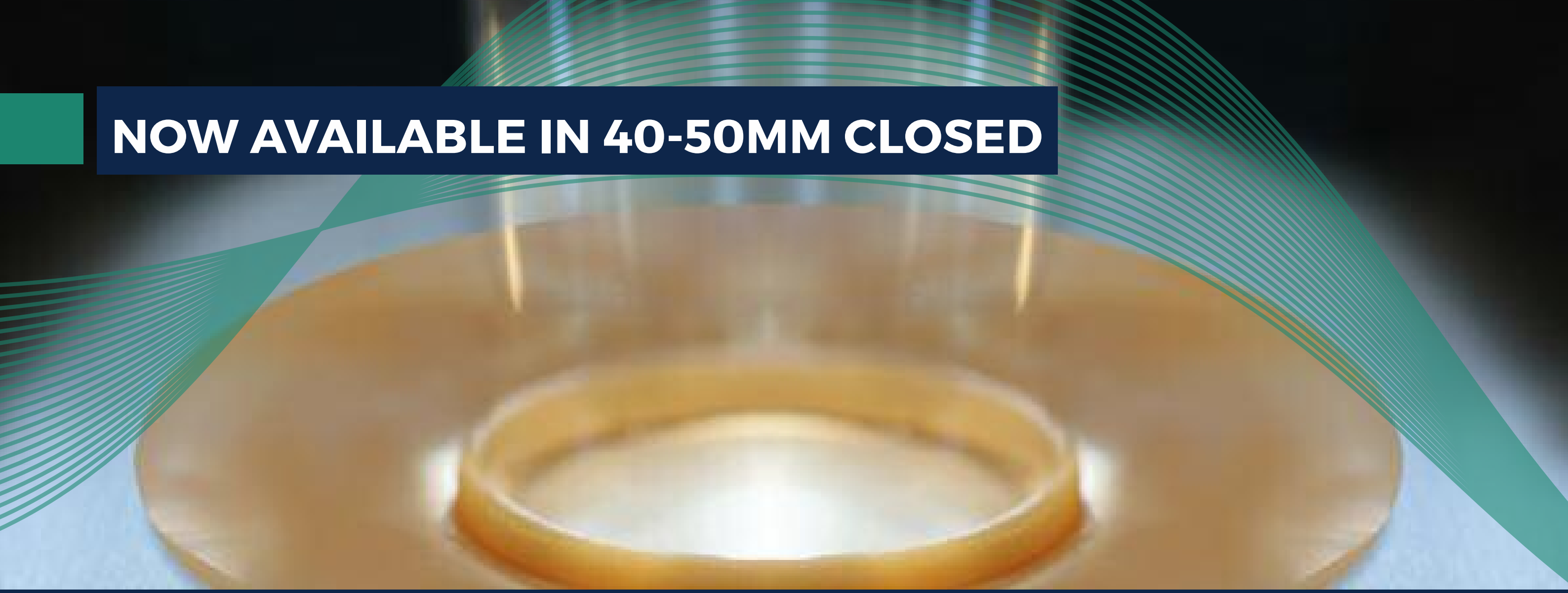
Nomination closing date 1st August 2016

Nominating your Stoma Nurse couldn't be easier, simply visit www.stomahero.co.uk to submit your online nomination and tell us why they deserve to be the next winner.

#stomahero2016

ConvaTec

Full terms and conditions can be found online at www.stomahero.co.uk. For all ConvaTec product or service enquiries please freephone 0800 88 50 50



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WITH MOULDABLE SKIN BARRIERS

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The convenience of a one-piece with the security and clinically proven[1] skin protection of our Mouldable skin barriers.

This combination helps people feel in control and gives them the freedom to get on with the other important things in life.

- **Secure** - The elastic-like seal securely hugs any stoma. Designed to minimise leaks for healthier skin.[1]
- **Simple** - Just roll, mould and hold to accommodate any stoma shape and size. No cutting, no stretching, no guesswork.
- **Comfortable** - Thin and flexible, designed to move with the body.
- Clinically proven skin protection[1].
- Tailored fit regardless of stoma shape.

ESTEEM™ +
Closed end pouch with Mouldable skin barrier

ESTEEM™ +
Drainable pouch with Mouldable skin barrier

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

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

colostomy association

Win up to £25,000 with Unity

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.
Winners have to match 3, 4, 5 or all 6 digits of the winning number in the correct place in the sequence.

How to join – three easy steps

Step one – Complete your personal details - so that we can contact you if you win.

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

Step three – Complete the direct debit instruction or enclose a cheque. Detach the form, put it into an envelope and return to **Unity** to the address shown on the right panel.

Unity will notify you of your **Unity** lottery number.

If you have any queries please call our hotline on
0370 050 9240

Results & Rules can be checked by visiting
www.unitylottery.co.uk

Or by phoning the Unity winners hotline
0370 055 2291

Calls cost no more than calls to geographic numbers 01 or 02.
You must be 16 or over to enter.

50p
From every £1 goes to Colostomy Association

Prizes

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

1. Your details (please print in block capitals)

Title:
First Name:
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**
Name and full postal address of your Bank or Building Society.

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

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

DD15

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

DIRECT Debit

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

Service User Number 4 2 1 1 0 2
Reference:

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.

Signature:
Date:

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

4. Your consent to Play (I confirm I am 16 or over and resident of GB)

16

Surname:
Date:

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

For office use only:

Detach the form, put it into an envelope and return to **Unity** to the address shown on the right.

They will notify you of your **Unity** lottery number.

Post this form to:
Freepost RLZR-GSYJ-KSZA
The Unity Lottery
Furness Gate
Peter Green Way
Furness Business Park
BARROW-IN-FURNESS
LA14 2PE

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

The Unity Lottery, Freepost RLZR - GSYJ - KSZA, Barrow-in-Furness I T: 0370 050 9240 I E: info@unitylottery.co.uk
Unity is operated by Sterling Management Centre Ltd, registered as an External Lottery Manager by the Gambling Commission under the Gambling Act 2005 – www.gamblingcommission.gov.uk

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

Each time we start to put this article together we're always pleasantly surprised and proud to see the numbers of people who are giving up their time to raise funds for the Colostomy Association. Young and old, volunteers, medical professionals, people living with a stoma and people without. From sponsored runs to cake sales, every contribution is priceless and very much appreciated.

Shelley's Party

In December, Philip Young, representing the Colostomy Association, visited the Stoma Care Department at Cheltenham Hospital to receive a donation of £700 from Shelley Smith, a Clinical Nurse Specialist in Stoma Care.

Five years ago at the age of 42, Shelley was diagnosed with breast cancer. She had three surgical operations followed by chemo/radiotherapy so understands the effects of neutropenia, fatigue and life after diagnosis. Shelley is now well and hoping for continued good health.

To celebrate her five year mark, Shelley held a celebratory party at the Cheltenham Lido with all donations kindly going to the **Colostomy Association.** Many of Shelley's stoma patients have generously donated to her fundraising and were surprised by her cancer story.

Thank you for the donation received and to the nurses in the Stoma team at Cheltenham Hospital for the continued care and support of their patients.

Carol singing for the Colostomy Association

Christmas is always a great time for a sing along and both St Peter's Church from Dulverton in Somerset and the Keyworth Choir (pictured in the next column, top) from Cotgrave near Nottingham raised their voices for the **Colostomy Association** in December 2015.

The congregation of St Peter's raised **£100** by carol singing around the village, while the Keyworth Choir raised **£400** from their carols around the streets and performance in the village square.

Have your cake and eat it

For the last four years **Colostomy Association** volunteer Caroline Emeny (pictured below with a Facebook Tomas bear) has held an annual cake stall in her home village of Laxfield every autumn to help raise funds.

Yet again, the array of delicious home made cakes was absolutely amazing. These included Christmas cakes and fruit cakes to lemon drizzles, chocolate, coffee & walnut, Eccles, sausage rolls, homemade soup, plus mince pies, brownies, crumbles and numerous other goodies!

The organisation involved in running an event including contributions from 33 different bakers who offer up numerous treats is difficult enough, but when you're also faced with some of the worst autumn weather on record descending on Suffolk during the day, the challenges involved were greatly magnified!

So, despite being banished to the church porch to avoid being blown away by the elements, everyone involved contributed towards a massive **£815** being raised. Our thanks go to the generosity of the residents of Laxfield and to Caroline's team of dedicated helpers.

Swim when you're winning

Back in October last year eight year old Lucy Bennion planned to swim an amazing 1,000 metres in support of her grandfather who has a colostomy. He set Lucy a challenging target of not only completing the swim but raising **£400** for the **Colostomy Association.** We're happy to report that Lucy passed with flying colours on both counts as not only were the 1,000 metres conquered but she more than doubled her fundraising target and raised an incredible **£851.50.** Well done Lucy!

Margaret's art attack

Margaret Simister (pictured overleaf) is a well known admin volunteer both in the office and at the end of a telephone and has been helping out since 2009.

In the autumn Margaret generously volunteered to give even more of her time to raise money for the **Colostomy**

CONTINUED ON PAGE 20, COLUMN 1

Fundraising Focus

CONTINUED FROM PAGE 19, COLUMN 3

Association. So on Wednesday 28 October 2015, she used her talent as an accomplished artist and organised a pastel portrait workshop.

The weekly Art Group at Phyllis Court Club in Henley–on–Thames assembled at 10:00am for the first of two sessions on black and white portraits. The aims were explained and Margaret asked for a donation In lieu of a tutor's fee. She provided two of her own head and shoulder portraits of ladies in 1920's hats and all the essential art materials to enable the attendees to produce their own artwork.

Many of the students who had never used pastels before were quite daunted. However, under Margaret's excellent and very patient teaching, some amazing results were produced. At the end of the two sessions Margaret had raised the princely sum of **£180.00** and the pictures were simply stunning!

Hair today gone tomorrow

David Taylor from Newton St Cyres in Devon will be feeling much lighter after having his hair cut off in aid of the **Colostomy Association.**

David (Pictured with **Colostomy Association** President, Ian Daniels) spent the whole of 2015 cultivating his locks for a sponsored hair grow. On 8 January this year David finally took the scissors to it and in the process he raised **£410** for the **Colostomy Association.** Many thanks go to David and to the Beer Engine Pub whose regulars helped contribute towards his target.

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 other people in this edition:

- **The Fareham Lodge** of Instruction kindly donated **£250.**
- **Erwash Bowls Club** raised **£180** from their annual match, when 48 players took part in a day that was played in great spirits. The members also received a talk from **Colostomy Association** volunteer Tore Norman.
- **The partners and Customers of Waitrose** branches in Reading and Witney have both been raising funds for the **Colostomy Association** and between them raised **£600.**

Do it for charity!

The **Colostomy Association** have teamed up with Skyline Event management to offer potential fundraisers the opportunity to take part in a wide range of activities and events for free, while raising valuable sponsorship money to help us continue to support people with a stoma throughout the United Kingdom.

For the adventurous amongst you who might have resolved to take up a challenge or do something different in 2016, the website **www.doitforcharity.com** has everything from fun runs to half marathons and charity cycle rides.

To see the fundraising events currently on offer from skyline and the **Colostomy Association** just log on to **www.doitforcharity.com/colostomyassociation.aspx**

Giveacar.co.uk

The **Colostomy Association** has teamed up with **giveacar.co.uk** in a scheme which can turn your old car into cash for any UK charity. They arrange free collection, then either sell your car at auction or scrap it with the proceeds raised going to your charity.

The UK's first car donation scheme, Giveacar has won several awards and has now supported over 1,000 charities with the money raised from old cars. Using a nationwide network of breakers yards and salvage partners, we have handled the auction and disposal of over 8,000 vehicles so we know how to raise the best donation possible whether your car is in perfect condition or not. If you need to get rid of an old car and would like to help the **Colostomy Association** at the same time visit **www.giveacar.co.uk** or call **020 7736 4242,** quoting **Colostomy Association** as your preferred charity.

Thanks to Mrs Chandler from Reading who used the service earlier in the year, the **Colostomy Association** have already had a donation from **giveacar.co.uk**

Textgiving

You can now make a donation to the **Colostomy Association** with a text message!

Whatever mobile network you're on, simply text our unique code **CASS01** and an amount of **£4, £5** or **£10** to **70070.**

Donating via text JustTextGiving by Vodafone is **free.** There is no cost to you for sending the text message and your free allowance or bundle will not be affected – the only charge will be the donation itself.

What's more, 100% of your text donation (including Gift Aid) will be sent to the **Colostomy Association.**

The amount you donate will be added to your mobile phone bill or deducted from your pay as you go credit. JustTextGiving will send you a link in a text message confirming your donation.

GIFT AID EXPLAINED

If reading this edition of *Tidings* has made you consider making a regular or one off donation to the **Colostomy Association,** you may be interested to know how just a simple tick in a box on the donation form can make your gift reach even more ostomates and at no extra cost to you!

CONTINUED ON PAGE 22, COLUMN 1

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Fundraising Focus

CONTINUED FROM PAGE 20, COLUMN 3

What is Gift Aid?

Gift Aid is a simple way to increase the value of your donation to the **Colostomy Association.** If you pay tax in the UK, the **Colostomy Association** can reclaim the basic rate tax (25%) on your gift. So, if you donate £15, it is worth £18.75 to us.

Here's our guide to a simple and straightforward way of making your donation go even further.

Do I qualify for Gift Aid?

In order for the **Colostomy Association** to reclaim the tax you have paid on your donations, you must have paid income or capital gains tax in the UK for each tax year (6 April to 5 April) at least equal to the tax that all the charities which you donate to will reclaim on your gifts for that tax year. You don't have to be in work to qualify. If you receive a state pension you are also eligible as that is taxed at source. Other taxes such as VAT and Council Tax do not qualify.

How do I sign up to Gift Aid?

The process is simple – all you have to do is make a Gift Aid declaration when completing one of the donation forms you can find in this magazine. You can also sign up if you are donating online through our website; just tick the Gift Aid box on the donation form. If donating by telephone you just need to confirm that you want to make a Gift Aid donation and we will do the rest!

What does the Gift Aid declaration commit me to?

Nothing! It just ensures that if you choose to donate to the **Colostomy Association,** we can claim an extra 25% back from the UK Government.

What is a Gift Aid declaration?

A Gift Aid declaration is a statement by an individual taxpayer that they would like a charity to receive the tax paid on their donation back from the UK Government.

How long does the declaration last for?

To simplify matters for both you and the **Colostomy Association,** the declaration wording normally covers present, future and past donations. We can back–claim payments made over the past four years and we will continue to claim until you tell us otherwise, so long as you are eligible.

What do I do if my tax status changes or I want to cancel my declaration?

To let us know if you stop paying tax or wish to cancel your declaration, please use the enquiry form on our website, write us a letter, send an email or call us on **0118 939 1537.**

Will making a Gift Aid declaration really make that much difference?

If you donate £15 a year you may think that an extra £3.75 to us through Gift Aid isn't really that much of a deal. But what if an extra one thousand people who were eligible also didn't sign the Gift Aid declaration? That means we would be missing out on an extra £3,750 a year. That's enough to provide refresher training for all our helpline volunteers and ensure our Freephone helpline can keep operating 24–hours a day for another year.

That alone should get a tick! ■

Legacy donation

A gift in your Will

If you are about to make a Will, or are considering making a change to your current Will, please consider leaving a legacy to the **Colostomy Association**. Your legacy could secure the Association's future and provide continued support to all those 'living with a colostomy' present and in the future.

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

Irrigation and you

Sarah Squire, Trustee writes: With summer hopefully around the corner some of us may be thinking about a holiday, either abroad or perhaps closer to home to visit friends, or one of the beautiful parts of the UK.

But how does travelling affect irrigation? I thought I would tell you about my experience of irrigation and travelling, and tips I have picked up on the way:

Irrigation can make travelling less of a worry, certainly on the journey itself. I am a born worrier. I don't mind travelling and love to go on holiday, but anything out of routine and my bowel is the thing that pipes up.

But irrigation means I am in control so I have peace of mind that as long as I stick to what I know doesn't upset me (ie don't drink a bottle of red wine the night before I fly), I'm able to travel with confidence. I normally irrigate in the evening as it suits my working day but if I am out and about I will change this to fit with my plans. It is advised to stick to a similar routine when first irrigating but once we get the hang of it, many of us can shift the schedule to suit what we are doing. So if I know I am having a long day of travelling I will either skip the evening and irrigate the morning we go, or if it is going to be an early start and a long day I might irrigate as normal the night before and stretch my irrigation to miss that day and do it the morning after we arrive at our destination.

Of course we are all different and some people only irrigate every other day anyway, and some can't stretch it to 36 hours. But I tend to look at the journey itinerary and have a think about what will work best for that day for me and make a plan from there.

Before we even leave home though, we need to think about what we need to take. Alongside our normal stoma supplies, irrigators who use a cap might want to pop in normal bags and even a few drainables in case of upset while away. I take a spare irrigation kit, plus more sleeves than I would need for the number of days away, in case of delays or mishap. I also carry an *S–hook* which is very useful for hanging the water reservoir, and a sticky hook for the occasion of nowhere to hang my *S–hook.* I have only needed to use my sticky hook once, in a bathroom in Cape Verde, otherwise the *S–hook* has served me well.

The bathroom was huge with nowhere to hang my trusty *S–hook,* but normally there is a shower curtain rail, door or towel rail which does the job fine. Speak to most irrigators and the first thing we do on entering a hotel room is check where we will hang the hook. But in the eight years I have been irrigating I have stayed in many many hotels and have always managed. If you remember, in an earlier edition of *Tidings* Brian Kirkby also described an easy to make lightweight telescopic pole which he takes away with him to hang the water reservoir from. Instructions of how to make it were shown in a follow up article in *Tidings* Spring 2015 if you would like to have your own. Some irrigators may use the pump of course, which eliminates the need to hang anything so may be seen as an advantage for travelling, although you need to weigh up the extra bulk of the pump versus a small gravity kit. It's all personal preference so choose the method which suits you.

If you are going to stay with friends it may be worth mentioning you'll need use of a bathroom for a while to irrigate. You may feel a little uncomfortable asking it but better to briefly explain so you don't feel rushed – we all know relaxation is the key to a good irrigation so you don't want to be worrying about the time you spend in the bathroom. I've always found friends have bent over backwards to help and have appreciated me being upfront as they want my stay to be a happy time.

If you are camping then irrigation may be more of a challenge. I have friends who irrigate very successfully in their camper van though, and if you are in a tent you may be able to use the disabled facilities on the site. Or alternatively you may choose not to irrigate while away and let the bowel do its own thing. You can pick up with irrigation once you get home.

We often get asked about irrigating with the water abroad. The simple rule is, if the tap water is safe to drink then it is safe to use for irrigation. If in doubt use bottled water. If you are in a country where it's the norm to drink bottled water it is usually very cheap to buy. If you are in a hotel you could ask for bottled water to be provided. When we went to Mexico a few years ago I emailed the hotel to request extra water be

CONTINUED ON PAGE 25, COLUMN 1

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☐ **HydroFrame** with Manuka honey
☐ **HydroFrame Mini** with Manuka honey
☐ **Hyperseal** with Manuka honey - small low profile
☐ **Hyperseal** with Manuka honey - small high profile
☐ **Hyperseal** with Manuka honey - large low profile

Mr/Mrs/Miss/Ms: ______ Initials: ______ Surname: ____________________ Address: ____________________
____________________ Postcode: ____________________
Tel. No: ____________________ Email: ____________________

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CONTINUED FROM PAGE 23, COLUMN 3

delivered to the room daily. I admit I was uncomfortable about telling them why so mentioned a medical reason, but after numerous emails back and forth saying no I didn't want sparkling water (!!!), just clean drinking water I finally said I had a colostomy and needed to do a daily bowel washout. I should've just said that at the beginning as they totally understood that and when I arrived in my room there was a line of water bottles on the dressing table and a fresh delivery daily. Likewise when we went to Cape Verde the year after, I sent a simple email, this time making it clear. I did laugh at check in though, as they'd allocated us a disabled room with a huge bathroom. But every morning a lovely man arrived with my extra water so I was a happy irrigator. When I know I will be using bottled water I take a travel kettle and an extension lead (plus plug adaptor)*. This way I can heat a little water and top up from the bottle to get the right temperature. Others have also suggested putting the bottled water out in the sun to warm up which could work well if you are in a hot climate. You can see my irrigation set up in Cape Verde in the photo *(pictured right)* Using my *S–hook,* bottled water, kettle and extension lead I was all set for a comfortable irrigation. Add a good book and some wifi to catch up with Facebook and I could relax and irrigate as normal.

This may all sound very complicated but it really doesn't need to be. When I am going away I run through a quick checklist in my head. What time are we going, how long will it take and what are facilities going to be like when we get there. It may take a little thought and planning but once that is all sorted hopefully you can forget about your stoma and enjoy your travels. Happy irrigating!

Sarah Squire

sticky hook supporting an S–hook with water reservoir underneath

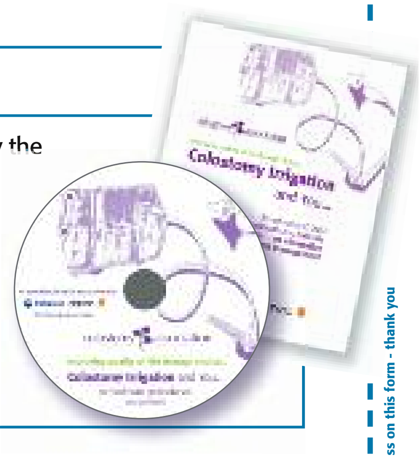
***Electrical appliances and extension cords are not recommended in wet areas and should be avoided.**

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

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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Used by kind permission of Hospices of Hope

A patient being examined and offered support in Moldova

Stoma Aid: "..they used household accessories for their stoma pouches..."

At the beginning of the year, our newest service – Stoma Aid – was launched. Stoma Aid is an initiative which will help thousands of people across the world who are unable to afford or who cannot access suitable stoma supplies.

Since the launch, we have been overwhelmed by the generosity of our supporters (and several manufacturers) with boxes of unwanted supplies being sent to our main warehouse in Bolton to be sorted and packaged.

Stoma Aid accepts unused and surplus supplies in the UK that cannot be returned to the NHS. These supplies are sorted at our warehouse in Bolton and then distributed through partner UK charities and organisations to ostomates in developing countries across the world.

One country where your supplies make a real difference is Moldova – where the **Colostomy Association** is working with Hospices of Hope to change the lives of thousands of patients.

Moldova is the most impoverished country in Europe with 13% of the population living on less than **£1.60** a day.

In the UK, stoma patients are provided with either without cost or affordable stoma supplies. In Moldova patients do not get pouches supplied to them, let alone the aftercare or accessories which help with basic hygiene and comfort. If they cannot afford to buy pouches they resort to using supermarket plastic bags or plastic bowls and are isolated from friends and family.

Hospices of Hope has been helping cancer patients in Moldova's capital city, Chisinau, since 2002. At their main centre, Hospice Angelus, over 1,580 stoma patients are in desperate need of stoma supplies to help them live a full and active life.

"Before patients heard about us," Hospice Angelus doctor Andrei says: "they used household accessories for their stoma pouches including unsterile plastic bags and bottles. Even finding places to buy stoma pouches is impossible and very expensive for patients."

However, the launch of Stoma Aid has helped improve the lives of stoma patients visiting Hospice Angelus.

The family of one Hospice Angelus patient, Dumitru, travels over 100km each month just to collect his stoma supplies. Writing to Stoma Aid via Hospice Angelus, Dumitru wrote: "I wanted to send a sincere thank you from the bottom of my heart for helping me by providing pouches for my intestinal stoma. Because of the low pension that I receive, I cannot afford to buy these myself. Thank you that you exist and that you help people like me."

Sadly, cases like Dumitru's are too common across the world where poverty and lack of infrastructure are forcing thousands of ostomates to use tin cans, crisp bags, bin bags and other improvised items.

Donations

Supplies donated to Stoma Aid will help transform the lives of patients in Moldova, Kosovo and Papua New Guinea. Make sure your unwanted supplies don't go to waste and send them to:

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

Stoma Aid **cannot accept** the following supplies: syringes, out of date items, prescribed medication or drugs of any kind. All two–piece pouches must feature both the pouch and the matching flange/base plate.

Remember: we must all manage our stoma supplies carefully and not over–order as this could save the NHS thousands of pounds each year. Only genuinely unneeded supplies should be donated to Stoma Aid as a result of reversal, allergic reaction, change of stoma shape or loss of a loved one for instance.

If you'd like to donate much needed funds to keep our overseas aid project going longer term, please send a cheque to the office, made payable to Stoma Aid.

Please contact the **Colostomy Association** if you require any further information. ■

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

Trio® Elite Sting–free Silicone adhesive remover and Elisse Sting–free Skin Barrier sprays

Trio® Elite Sting–free Silicone adhesive remover and Elisse Sting–free Skin Barrier sprays and wipes are now available on prescription.

Elisse Sting-free Silicone Skin Barrier protects skin from body waste to prevent irritation and breakdown. Elisse soothes reddened skin and reduces itching.

Elite Sting–free Silicone adhesive remover is gentle but highly effective whilst leaving your skin smooth and undamaged.

Try it yourself and Tell us what you think by ordering some **FREE** samples. Simply call **0800 351 6280**, email on **customercare@triohealthcare.co.uk** or visit **www.TrioOstomyCare.com**

NEW

Appeel Advance Spray – pouch removal at any angle

Market leading Appeel Medical Adhesive Remover which helps you to easily remove your stoma pouches without damaging your skin, is now available as new Appeel Advance Spray.

The spray uses the same superior Appeel fluid, specially blended from healthcare grade silicones for optimal removal each and every time, in a new bag–on–valve can design for 360˚ application.

Appeel Advance Spray offers new and exciting benefits that will help to make pouch removal even easier:

- 360˚ delivery – use in any direction even upside down
- No cold sensation – comfortable application for sensitive skin
- Quieter spray – discreet use
- 100% usage – no product remains in the can

FREE SAMPLE

Call the CliniMed Careline **0800 036 0100**
or email **enquiries@clinimed.co.uk**

News From the Office

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First name ....

Surname ....

Address ....

....

....

....

Postcode ....

Tel no ....

eMail ....

Please return payment, ticket stubs and unsold tickets no later than **Friday 16 December 2016** to: Colostomy Association, Enterprise House, 95 London Street, Reading, RG1 4QA.
Draw to take place on: **30 December 2016** at **Colostomy Association, Enterprise House, 2nd Floor, 95 London Street, Reading, RG1 4QA**
Late entries will be treated as donations.

colostomy association
Helping ostomates since 1967

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£1 Ticket 5 per book

Annual Prize Draw
Your chance to win

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2nd prize £500

£250 x 4 prizes

Draw date: **Friday 30 December 2016** around 12:00noon
at **Colostomy Association, Enterprise House, 2nd Floor, 95 London Street, Reading, RG1 4QA**
No tickets may be sold by or to anyone under 16 years. No tickets may be sold on the street.
Promoter: Mr Monty Taylor, Colostomy Association, Enterprise House, 95 London Street, Reading, RG1 4QA
Winners will be notified by telephone, email or post and announced in the Spring 2017 edition of *Tidings*
Lottery Licence no: LOT000141
Colostomy Association is a charity registered in England and Wales No: 1113471

Each quarter we like to share our latest news and this Spring there are plenty of achievements for us to be proud about.

NEW Sport and Fitness after Stoma Surgery Booklet

Are you looking for ways to stay fit after undergoing stoma surgery? We are pleased to announce the launch of our new *Sport and Fitness after Stoma Surgery* booklet.

This guide contains information on simple exercises you can do at home as well as information on a range of sporting activities from swimming to yoga. The booklet is perfect for anyone looking at getting back into exercise following surgery.

A spokesperson for the **Colostomy Association** said: “We’re always looking at new ways of enabling ostomates to live a full and active life and are very proud to announce the launch of our new booklet designed to encourage thousands of patients become more active.”

The booklet is completely free of charge to receive. Please download a version from the **Colostomy Association** website to save us postage or contact the office if you are thinking about exercising and would like your own copy.

Raffle tickets

Enter the **Colostomy Association’s** 2016 raffle to be in with a chance of winning **£2,500** at Christmas.

For just £1 you could win some spending money this December; perfect for Christmas shopping or a last–minute holiday.

All money raised from the raffle will go towards supporting vital **Colostomy Association** services such as our 24–hour helpline, range of free literature and *Tidings* magazine.

In addition to the **£2,500 main prize**, runners up could win **£500 for second place** or **four chances of winning £250** each.

Inside this edition of *Tidings* magazine you will find two £5 raffle ticket booklets. To enter simply fill out your details on the tear off slip and mail that section back to us along with your donation – it couldn’t be easier.

CONTINUED ON COLUMN 3

CONTINUED FROM COLUMN 2

All ticket sales need to be in by **Friday 16 December 2016** with winners notified by telephone, email or post and announced in the Spring 2017 edition of *Tidings*.

Audio version

The **Colostomy Association** is excited to announce that we are now releasing an abridged audio version of *Tidings* for supporters with poor vision. Our audio version of *Tidings* will feature the top stories from each edition, read using special text to speech software. Each issue will be uploaded one month after print release. Have a listen to the last version of *Tidings* by visiting:

mixcloud.com/colostomyassociation

CONTINUED ON PAGE 30, COLUMN 1

£1,000 • £1,000

500 Club – LAST DRAW December 2015 Draw Winners!

Mrs Holness	£	1000.00
Mrs Cooke	£	228.00
Mrs Bullock	£	114.00
Mr Foulger	£	45.60
Anonymous	£	45.60
Anonymous	£	45.60
Mr Murray	£	22.80
Mr Omar	£	22.80
Anonymous	£	22.80
Anonymous	£	11.40
Anonymous	£	11.40
Anonymous	£	11.40

NOTE:

The following people also kindly donated all or part of their winnings back to the Colostomy Association: Mrs Holness donated £250; Mr Murray donated £22.80 (all of winnings); Mr Foulger donated £25 and Mrs Cooke donated £20.

Win up to £25,000 with the new Unity Lottery – see page 18 for details.

News From the Office

CONTINUED FROM PAGE 29, COLUMN 2

Photo Competition for 2017 Calendar – CLOSING SOON!

There's still time to submit your holiday photos for inclusion in our 2017 calendar.

We want to show that having a stoma shouldn't limit people's ambitions with scenic photos of ostomates' travels across the world.

We are looking for digital photos of around 4,961 x 3,508 pixels or files over 3Mb in size should be of sufficient high quality. All photos must be landscape and along the lines of our scenery theme. We welcome photos from all types of travel, whether in the UK or abroad.

Make sure your high resolution photos are sent in by 30 April 2016 to: **editor@colostomyassociation.org.uk** to qualify for first the place prize of a free wall canvas. Those judged as being second and third place will each receive a free calendar. Information on how to order our 2017 calendar will be included in our Summer edition of *Tidings.*

Readership Survey

The **Colostomy Association** is researching the quality of life of ostomates living in the UK and we need your help.

We would like to know what impact a stoma has on your day–to–day life, so please take a few minutes to fill out our survey on the pull–out section in the centre of the magazine. Your responses will be incredibly invaluable for providing statistical evidence for press releases, adding strength to our campaigns and improving our services so we can support you all the more. Ideally, we need at least 1,000 responses to make this survey a realistic representative sample of the population so please help us. As an incentive, a **£50** Debenhams voucher will be awarded to one lucky person, if they happen to give their contact details on the completed survey. (This voucher was kindly donated back to the **Colostomy Association** by the previous winner!) If you prefer to complete an online version of the survey, please go to: **http://goo.gl/forms/DJTegIwvfv**

Closing date 30 June 2016.

Manufacturer mailings

Since subscribing to *Tidings* magazine you may have received some promotional correspondence about manufacturers' events or products which we hope has been beneficial to you. This mailing service is handled by our office and all money received goes towards covering the cost of vital **Colostomy Association** services like our 24–hour helpline and range of free literature that includes this magazine. We strictly comply to Data Protection laws and your data is not passed on to any third parties.

Remember, you can always opt–out of this mailing service, but it is a good way of finding out about new products and local events. Please write in or contact the **Colostomy Association** if you do not wish to receive any third party promotions.

Stoma Friendly Society update – Airport security

Our campaign to create a stoma–friendly society continues to succeed with the **Colostomy Association** now helping to train up airport security staff on how to respond to people with a stoma.

In a period of increased security due to terrorist threats it is not surprising that some ostomates will be stopped and searched because of their stoma bag. However, we want to make sure anyone with a stoma is treated with respect during a security search.

The **Colostomy Association** are working with airport security staff at Birmingham, London City and Luton airport (so far) to make sure that no ostomate has to face embarrassment in front of fellow passengers while travelling.

Accessible toilets

Since we announced our Stoma–Friendly Society Campaign in the previous edition of *Tidings* magazine, we have been receiving emails and calls from supporters who are keen to get involved.

Supporters across the country have been contacting their local councils, lobbying MPs and raising awareness about the issues they've faced on social media.

Len Faulkner contacted Hastings Council after he was forced to kneel on the floor to change his bag as there was no other surface space available (as the cistern had been built into the wall and there was no toilet seat lid). He is currently awaiting a response to his complaint.

Irene Constable in Shropshire contacted her local MP over the lack of adequate facilities for ostomates in her area. Irene's letter, along with her recommendations, were passed onto the Shropshire Association of Local Councils.

Similarly, Caroline Richards shared her story on Facebook of changing her stoma bag on the floor – it was shared over 13,000 times and received coverage in the Metro and the Mirror online. As a result of this success, Madeleine Moon MP raised the issue of stoma–friendly loos in Parliament.

Have you had any issues using loos as an ostomate? Would you like to lobby your MP, local council or share your story online? Get in touch for help and assistance from Niall Norbury at the **Colostomy Association.**

Do you have a story or article for Tidings?

The editorial team always welcome submissions from our readers:

- Stories of how you came to have a stoma and how you cope with it
- Articles on topics related to stomas
- Letters for the *Readers' Writes* page
- Questions for the *Dear Nurse* page

In future issues we are planning to cover:

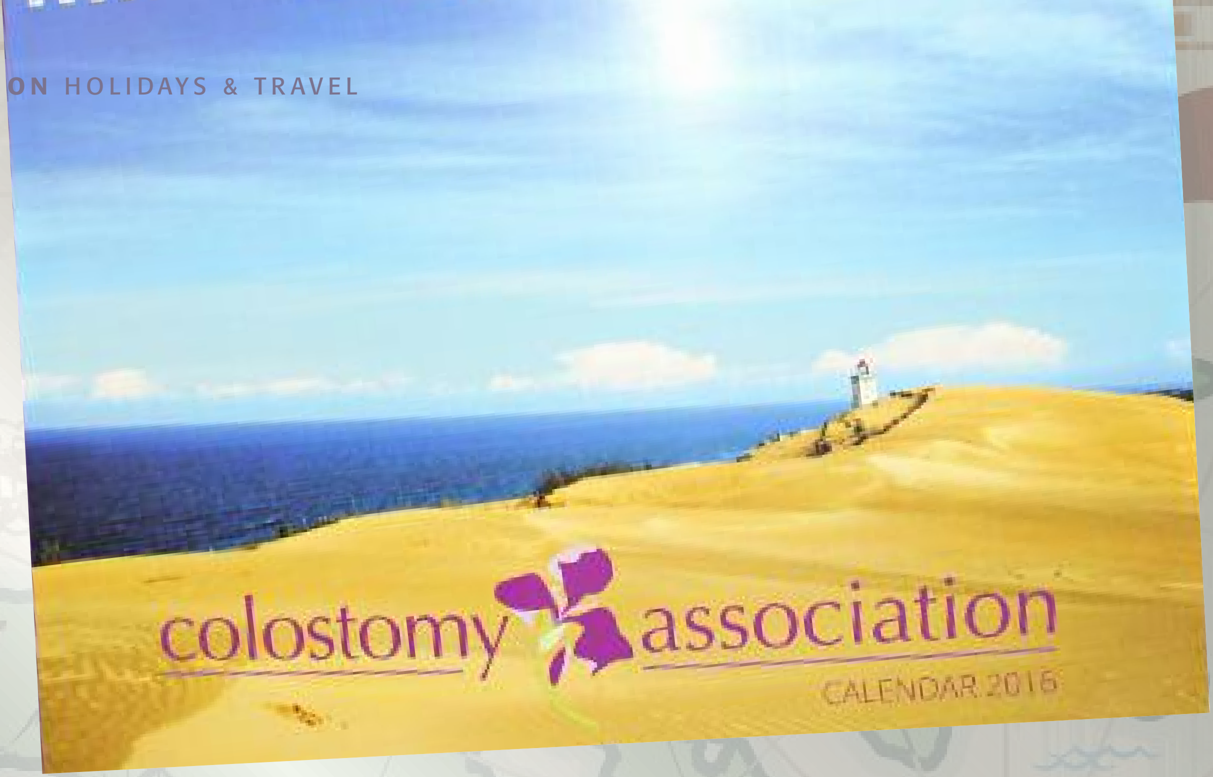
- **Diverticular disease**
  If you had your stoma due to this condition, do write in and tell us about it
- **Colostomy Association's 50th Anniversary**
  Next year we'll be celebrating *helping ostomates since 1967* by going back to our roots as the Colostomy Welfare Group. We hope to feature stories of people who had their stomas in the 1960s and 1970s when the Colostomy Welfare Group, as we were known then, first began supporting people living with a stoma.

Please submit your article (in no more than 1,200 words) to the editorial team at the address given at the front of the magazine. We hope to hear from you soon! ■

Eight page Travel Feature

Special Feature: Holidays & Travel including

- **Kevin Young**
  Winner of this years’ CA calendar photo competition
- **Cruising**
  is so easy for ostomates
- **Wherever we park the van is our home**
  David Ford
- **Tips for travelling when you have a stoma**
  Sarah Squire
- **Don’t forget your travel certificate**
- **Living Life to the Full**
  Crisi Taylor
- **Your travel insurance questions answered**
  Peter Martin



They say life begins at 40. For me it was 35, when I had my ileostomy – but that isn't the whole story.

Diagnosed with Crohn's disease aged 17, the painful mouth ulcers that appeared from nowhere would eventually also pockmark my gullet, wreck my large intestine and (somehow) paralyse the sciatic nerve in my left leg.

I tried to live as normally as possible and one way to escape from my health, and the peculiar hours I kept as a journalist, was to escape. Travel was always a great love and a thirst for discovery meant there was always somewhere else to be explored.

In many ways these were more innocent times – I remember at the turn of the century walking up to the White House, handing over $10 and taking a tour, and in the Middle East I seldom felt threatened – but travelling the globe was generally expensive until budget airlines took off.

Buoyed by the ability to pop over to the continent for £30 return, I took a year off at the age of twenty–seven and packed my suitcase. I was experiencing the beauty and civility of picturesque Scandinavian waterfronts, old–fashioned Eastern Bloc nations still coming to terms with freedom, and long lunches in tiny French bistros. It was bliss.

Trips further afield expanded my horizons further, from the neon lights and indecipherable hieroglyphics of Tokyo to the dusty chaos of Delhi and Christmas in the Australian sunshine.

There were, however, many lows. Narrowly escaping serious injury in a car crash near Beirut was certainly among them – top tip: it's never a good sign when your taxi driver tries to overtake on a narrow, winding mountain pass at 70 mph – but mostly my problems were closer to home.

Heavily reliant on steroids to control my illness, I would be either gaunt or puffy; fatigue and pain would destroy my energy levels and appetite; and the constant need to be near a toilet, or at least to know where to find one quickly, affected my confidence and mobility.

It was one thing to have travelled all the way to Roman ruins on Libya's coast or the Great Wall of China, but another to know I could manage a couple of hours without a toilet.

There were many times when I felt debilitated, but I was determined not to let my illness ruin my life. As so often with Crohn's, though, I reached a stage where surgery was the only option; my body kept trying to poison itself and the strain of fighting each new outbreak was taking its toll.

Deciding whether to have a stoma was enormously tricky and an issue I had tried to avoid for years. I feared my body would be wrecked forever and considered it a defeat, despite the endless patience and reassurance of the Whittington Hospital's gastro team.

By the time of the operation in 2008 I was desperate to escape the pain and the hold my illness had over me, and almost threw myself at the surgeon who had known for a decade that this moment was coming.

One inadvertent benefit of waiting for so long was the fact he could use the latest keyhole technology, and having pictured myself with a scars resembling the aftermath of a shark attack, I was stunned at how "normal" I looked.

My recovery was not as full as hoped, however. My colon continued to be troublesome, even though it was now being bypassed. Its removal 18 months later involved yet another long operation ("Your ileostomy was two out of 10 in terms of difficulty," my surgeon said. "This one is eight or nine."), time in intensive care and a long recovery.

This, though, really was the point where everything finally worked out. I gained the independence that had been missing from my entire adult life, along with seemingly endless energy and greater confidence. I also met my beloved Clare, now my wife, whose patience and devotion quickly eliminated any concerns I had that nobody would accept me with a stoma.

Dusting off my passport I was able to enjoy two extremes, both in terms of temperature and geography. Seeing the 12 Apostles standing proudly in the 45°C (109°F) heat was the highlight of a journey along Australia's Great Ocean Road, while it was so far below freezing beside the spectacular snow–covered waterfall at Gullfoss in Iceland that my camera stopped working.

I kept seeking hidden gems, and the photo which – I'm proud to say – adorns the front of this year's **Colostomy Association** calendar was certainly one of those.

Rubjerg Knude is so much a part of northern Denmark's coast that it will fall into the sea in the coming years when the cliff erodes.

The picture itself was an accident, after I inadvertently chose the wrong car park and found myself trudging through sand dunes on an unexpectedly lengthy approach to the lighthouse.

It all worked out, though – and that's as good a mantra as any for life with a stoma. Armed with perseverance and a sense of adventure, there's nothing to stop you doing whatever you wish.

Kevin Young

Foreground: The Blue Mosque, Istanbul

Cruising is so easy for Ostomates

The alarm broke our sleep at 4:30am. Suddenly I remembered today was my big day. My husband and I had always wanted to go on a cruise but having a permanent colostomy operation three years before made me very hesitant to say the least. I finally bit the bullet and we had booked the three week cruise for September 2012. It was too late now to change my mind!

The taxi was to pick us up at 6:00am and I was very worried that my colostomy would not perform so early in the day. We were to travel on a coach for six hours with the first stop three hours away.

I use flushable pouches, which are brilliant and so easy to use. I decide to ring the company who supply them for advice knowing my journey from home to port was going to be a lengthy one. They were very helpful and suggested I use extension strips for added protection, as this would give me more confidence.

Next I spoke to the **Colostomy Association** for help on possibly controlling the output. They too were very helpful and advised me to try different foods to see which gave the best results in reducing my output. After several trials of eating different foods, I found eating less fibre helped me. Two days before departure I ate less fibre and on the day prior to departure I ate very little fibre. This worked fairly well for me and I was ready when the taxi arrived. I had no problems at all on the coach going down to Southampton.

I took two and a half times the number of pouches I usually need, including a few drainable ones in case of a tummy upset. All these were packed in a hand–held flight bag, which I took with me on board the coach for safety.

When booking the cruise I filled in a medical form at the travel agents, informing the cruise company, P&O, about my colostomy. P&O did not want me to flush my bag on board ship so I was provided with a red plastic bag in the bathroom. I always wrapped my used pouches in my own disposal bags first and then popped them into the red bags which I think identified how the contents should be dealt with, as the cabin steward changed the red bag each time I placed a used pouch inside it.

The first two days I was slightly constipated but soon resolved the problem by eating some of the delicious chocolate cake which I usually dare not touch! The food on board was great with a huge variety available in the self service restaurant, which was open all day long. In the evening, if you chose to eat in the restaurant where you were waited on, the Maître d' will help out if the menu does not suit you.

Cadiz in Spain was our first port of call; built in the 12th century BC it is the oldest inhabited city in the western world. Three days later we were in Greece docked at Piraeus. The temperature was in the 90s and the walk to the top of the Acropolis was too much for us. Instead we walked round the old town of Plaka and took a miniature train ride round the streets.

The highlight of our cruise was the magical and mysterious city of Istanbul. A city of many contrasts, it is the oldest crossroads in the world, built astride two continents; Europe and Asia. We visited the world famous and incredibly beautiful Blue Mosque.

We went ashore at every port on our own and managed very well. I always took my emergency pack of spare pouches with me. These fitted easily into a small makeup bag and then into my rucksack. If I was concerned I may need to change whilst ashore I always wore a drainable pouch. As it turned out, I never had to change whilst away from the ship.

I also always took bottled water ashore with me together with some sandwiches, wrapped in a serviette, and fresh fruit from the self service restaurant. I checked with a waiter if this was allowed and it was never a problem. This enabled us to have a picnic in a place of our choosing and saved time, which is precious when ashore. Also it saved me from having to consider if eating and drinking ashore would give me an upset tummy. This worked really well for me.

Our last port of call was Palma in Mallorca, the largest of the Balearic Islands. The arrival by sea is spectacular with the famous grand limestone cathedral towering above the old town.

The next day we sailed for home. The holiday had been just about the most wonderful experience we have ever had. We will never forget our cruise and all the different ports; Nineteen days of glorious blue skies and sea. The holiday of a lifetime, I can't wait for the next cruise!

Mary

David's wife, Rosemary, relaxing after a hard day's sightseeing in York

Wherever we park the van is our home

We had always been an enthusiastic family for camping. Unfortunately I was diagnosed with bowel cancer in 2005 which resulted in surgery to remove my lower bowel, and form a colostomy. Whilst I was recovering I discussed with my wife, Rosemary, how we could continue our camping lifestyle. We agreed to think about buying a campervan.

We decided on certain criteria: it was going to be solely for ourselves, it had to fit on our drive, ready to take off at a moment's notice, and we were only going to use it for exploring the UK. In our search we were impressed by the Autosleeper, Ford Duetto. We subsequently bought one which was six years old.

It has given us wonderful service over the past 10 years and taken us to so many places we would otherwise never have visited. We always put our bikes on the rack at the back which gives us a chance of cycling as well as walking. From the start Rosemary has kept a small diary of the places that we have visited; brief notes about the campsite, nearby hostelries and historic sites together with thumbprint photos. Last Christmas I put it all together in a photobook reminding us of the last 10 years of exploring the UK in our van.

We try and walk coastal paths at least twice a year and have covered many of the paths in Pembrokeshire, Dorset (Golden Cap), Cornwall, Devon, North Wales and Norfolk. We have even camped on Upper Chorlton Road in Manchester! The van has given us complete freedom in allowing us to choose where we want to visit.

In the van we are self–sufficient, having a cooker, fridge, gas heating, shower, toilet and washing facility with enough water to allow us two nights (three days) freedom to camp wherever we want if no campsite is available. The shower/toilet cubicle in a campervan is quite small, which can make it difficult to change a pouch. However, the toilet door swings out and can be secured to the opposite side of the van making a small changing area. The sink cover provides a flat surface and there is water available from the wash hand basin in the toilet area. If a site has toilet facilities I use them. All sites have chemical toilet disposable areas and freshwater. Most of them have a waste pick-up so pouch disposal is no problem.

Whenever you are travelling as a stoma patient you are always concerned whether you have enough supplies and if there will be public toilets or, better still, disabled toilets available. When travelling in the campervan you take all of these with you.

No need to worry about being stuck in a massive traffic jam. You can just turn the seats around, put the kettle on, if necessary use the toilet and even change your pouch in comfort.

Although we had visited Scotland many times, in getting there we had always driven through Northumberland without ever stopping to explore the county. So just over a year ago we decided that we must make the trip from our home in South Wales and spend a few days taking in some of the sights on the eastern side of the country.

Driving north east on the A46 we called in for a cup of tea with our son and his family in Kenilworth. Then on to Lincoln, where we found our campsite, set up our pitch then drove into the city and parked up in one of the cobbled streets near the castle and walked to the Cathedral – a wonderful building and a chance to see the Magna Carta.

Next stop Scarborough. Never been there before but somebody told us it was a bigger version of Barry Island so we should be at home there. We stopped and made a cup of tea just underneath the castle across the road from the North Sea but did not see either because of the fog! Then on to Whitby, where we could not have asked for more appropriate weather, because this is where Bram Stoker wrote Dracula!

No fog next morning, just a cloud–free horizon. On to Northumberland; Castles everywhere. (Are we back in Wales?) We decided to make a stop in Craster, kipper capital of the north. Great campsite and only a short walk into town; supper in the pub and a few beers.

Next day a short trip to Alnwick Castle – we stood and looked in awe at this majestic building. To think that it has been in the same family for about 800 years. Amazing. If you are a Harry Potter fan this is the place for you. You can even learn to fly a broom stick; they give lessons.

We had planned our day trip to Lindisfarne carefully so that the tide was out when we made the early morning crossing on the causeway and the tide was in when we were walking around the island. The castle is not to be missed, and have a close look at the shed; they are made from upturned boats. When the tide went out we crossed the causeway back to Seahouses and had supper in the village.

It was a long drive back to York but this has got to be the best campsite because it is only about 100 metres from the city walls. Being a Caravan Club site it is very busy and advance booking is essential. However, it is the best site for visiting the city: York Minster, Viking museum, Castle museum, Railway museum, The Shambles, more chocolate than I have ever seen. Did we see everything? Definitely not, so another visit will have to be scheduled.

Leaving York the next morning we had to make one more stop in Yorkshire: Harrogate and a cup of tea and a bun in Betty's Tea Room. After a walk around the town, onwards to Kenilworth to stay with our son, his wife and the grandchildren. Best campsite of the holiday; park on their driveway and hook up.

Then home again, but not for long. Rosemary will tell you that every week I ask if we have any free time to get away. If we haven't been touring in the van for a while I get withdrawal systems, go out for a drive, park up, make a cup of tea, sit down and look at the scenery

David Ford

Readers' Feedback Questionnaire

Please complete, pull out from the magazine and return in the envelope provided in the magazine or post to: Colostomy Association, Enterprise House, 95 London Street, Reading, RG1 4QA by the end of June 2016.

The Colostomy Association is researching the quality of life of ostomates living in the UK. We would like to know what impact a stoma has on your day–to–day life as well as what you feel the public perceptions of people living with a stoma are.

Please take a few minutes to fill out our survey. Your responses will be incredibly invaluable for improving Colostomy Association services, providing evidence and adding strength to our campaigns.

Please complete this survey and return it in the enclosed envelope to the Colostomy Association by the end of June 2016.

A £50 Debenhams voucher will be awarded to one lucky person, if contact details are provided on the completed survey.

Ability

1. As the result of having a stoma have you ever found the following difficult in the past year?

	1 Not at all difficult	2	3 Somewhat difficult	4	5 Very difficult	Not applicable
Travelling within the UK	○	○	○	○	○	○
Travelling abroad	○	○	○	○	○	○
Meeting new people	○	○	○	○	○	○
Maintaining a relationship with friends and family	○	○	○	○	○	○
Attending social events	○	○	○	○	○	○
Having an enjoyable sex life	○	○	○	○	○	○
Performing duties at work	○	○	○	○	○	○
Finding or changing jobs	○	○	○	○	○	○
Enjoyment of hobbies and interests	○	○	○	○	○	○
Taking part in physical activity and sports	○	○	○	○	○	○

2. As the result of having a stoma, have you felt restricted in any of the following areas in the past year:

	1 Not at all	2	3 Somewhat	4	5 Very restricted	Not applicable
Travel	○	○	○	○	○	○
Diet	○	○	○	○	○	○
Choice of clothing	○	○	○	○	○	○
Job opportunities	○	○	○	○	○	○
Social activities	○	○	○	○	○	○
Sporting/physical activities	○	○	○	○	○	○

3. As a result of having a stoma, have you had to:
(TICK ALL THAT APPLY)

☐ Reduce the amount of hours you work
☐ Change your job
☐ Stop working altogether
☐ Been turned down for a job
☐ None of the above
☐ Not applicable, as not employed

4. Have you changed your style of clothing because of your stoma?

○ Yes, a great deal
○ Yes, somewhat
○ Yes, only a little
○ No, not at all
○ Unsure

Continued overleaf...

Readers' Feedback Questionnaire

Social

5. **How comfortable do you feel talking about your stoma with:**

	1 Very uncomfortable	2	3 Neither Comfortable nor Uncomfortable	4	5 Very comfortable	Not applicable
Current Partner	○	○	○	○	○	○
Family	○	○	○	○	○	○
Friends	○	○	○	○	○	○
Medical Professionals	○	○	○	○	○	○
Support Group	○	○	○	○	○	○
Stoma charity	○	○	○	○	○	○
New Partner	○	○	○	○	○	○
People online	○	○	○	○	○	○
Work Colleagues	○	○	○	○	○	○

6. **Have you ever experienced discrimination because of your stoma?** (TICK ALL THAT APPLY) (rudeness, criticism, sarcasm, mockery, unkindness, etc)

☐ **At work**
☐ **In public**
☐ **Online**
☐ **At home**
☐ **I have not experienced any discrimination**

If yes, what was your worst experience:

7. **Do you think having a stoma is a taboo subject in the UK?**

○ **Yes**
○ **No**
○ **Don't know**

8. **Do you believe attitudes towards people with a stoma are:**

○ **Improving**
○ **Staying the same**
○ **Getting worse**
○ **Don't know**

9. **Have you ever been challenged or criticised for using a disabled toilet?**

○ **No**
○ **Not applicable** (I have not used a disabled toilet)
○ **Yes** (please give details)

10. **Have you ever experienced problems with airport security as a result of having your stoma?**

○ **No**
○ **Not applicable**
○ **Yes** (please specify)

11. **Is your stoma classified as:**

○ **Temporary**
○ **Permanent**
○ **Unsure**

12. **Do you pay for your stoma supplies?**

○ **Yes**
○ **No, they are free**
○ **Unsure**

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Psychological

13. How have the following changed since your stoma operation?

	1 Significant worse	2	3 stayed the same	4	5 significantly improved	Not applicable
Confidence	○	○	○	○	○	○
Body image	○	○	○	○	○	○
Mood	○	○	○	○	○	○
Mental well-being	○	○	○	○	○	○
Relationship with partner	○	○	○	○	○	○
Relationship with family and friends	○	○	○	○	○	○

14. Do you feel you currently have control of your life?

○ **Yes**
○ **No**
○ **Unsure**

16. In the past year, have you ever attempted suicide or self-harm as a result of having a stoma?

○ **Yes**
○ **No**

15. As a result of having a stoma, have you had any suicidal thoughts in the past year?

○ **Yes**
○ **No**

17. Do you use any of the following Colostomy Association services? (TICK ALL THAT APPLY)

☐ **Tidings Magazine**
☐ **Literature and Factsheets**
☐ **24–Hour helpline**
☐ **Junior Ostomy Support Helpline (JOSH)**
☐ **Closed Facebook Support Group**
☐ **Stoma Aid**

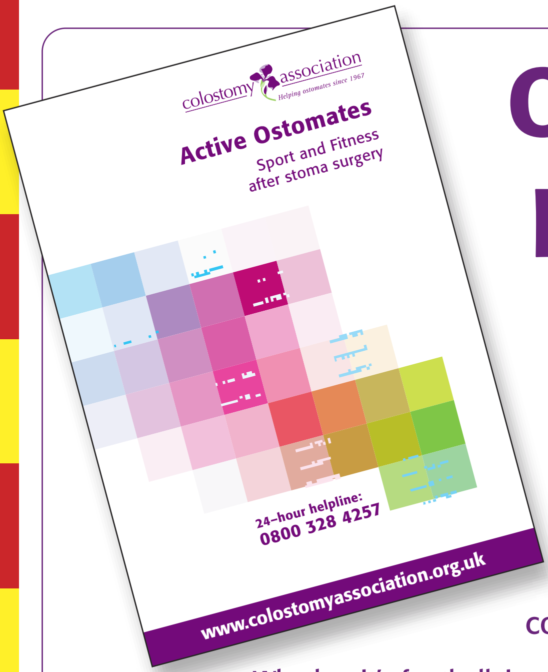
19. Do you have any other feedback or suggestions?

18. Please indicate if there are any improvements the Colostomy Association could make to any of its services

If you are happy for us to follow up your response to this survey then please include your contact details below. (Optional)

Title: **First name:** **Surname:**
Telephone:
Email:

Thank you for your feedback.



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colostomy association

Which would you choose?

Stay up to date – sign up for e-newsletter

Is hearing from us once a quarter not enough? Sign up for our monthly e-newsletter for all the latest news and information from the **Colostomy Association** straight to your inbox.

Our e-newsletter contains updates from the **Colostomy Association** as well as news on the stoma industry. Simple and informative – our e-newsletter arrives in inboxes on the last Friday of each month.

Leave your name and email address below to sign up today:

Name:

Email:

Thank you for your feedback.

Please complete, pull out from the magazine and return in the envelope provided in the magazine or post to: **Colostomy Association, Enterprise House, 95 London Street, Reading, RG1 4QA** by the end of **June 2016.**

Please complete, pull out from the magazine and return in the envelope provided in the magazine or post to: **Colostomy Association, Enterprise House, 95 London Street, Reading, RG1 4QA** by the end of June 2016.

Tips for travelling when you have a stoma

Going away from home for the first time post op can be a daunting prospect for an ostomate. Whether it is camping, caravanning, a business trip, a few days at a B&B or a long haul flight to an exotic location many of us worry about that first trip away.

How will I cope with the bag? Where will I dispose of it? How many should I take? Can I go swimming? So many uncertainties can be off putting as let's face it, you feel safe at home, so maybe it's better not to go away? Not at all! I think it's fair to say many if not most of us have thought long and hard about going on holiday with a stoma. But actually, a bit of planning and there is absolutely no reason a stoma should stop you enjoying a trip away as much ever. In fact I think a relaxing trip should be prescribed after each surgery as part of the recovery!

Let's start at the beginning and planning your stoma supplies. When going away we recommend you take twice the number of supplies you'd usually use during that time period and if you normally use closed bags, take a few drainables too in case of upset (or in my case more likely over indulgence!) Sachets of Oral Rehydration Salts eg Dioralyte, Electrolade etc when mixed with water will replace fluid lost due to diarrhoea and prevent dehydration. So it is a good idea to pack some of these – especially if you are going to a hot country. If you irrigate you may like to take a spare kit and a trusty hook. There is more info about travelling for irrigators on page 23.

It is a good idea to pack a small kit to carry with you for the journey, or trips out once at your destination. You could add small sachets of cleansing gel in case you need to change your pouch in a toilet cubicle where no water is available. A small amount of gel on a piece of toilet paper can be used to clean round the stoma and when your bag is in place the rest used for your hands until you are able to wash them properly in a hand basin. Several of the appliance manufacturers and suppliers now produce sachets of these no rinse, cleaning gels.

And remember a RADAR key will give you access to all accessible toilets in the UK, where there's always a wash basin and a bin to dispose of used appliances. See page 15 for details of how to obtain one along with an ID card.

If you are flying we recommend you take your supplies in hand luggage. You may be able to get an increased hand luggage allowance by contacting the airline before you fly or if you are with a group may find the normal allowance is plenty spread between you all. Liquids and gels, including aerosols **CAN** be carried in hand luggage as long as they are no more than 100mls and are placed in a clear resealable bag up to 20x20cm sized which you must remove at security and place in a tray to be x–rayed. If you don't follow those guidelines they may be confiscated. Some scissors can also be carried in hand luggage now so check the airport website for details. On the subject of airport security, many of us worry about what will happen with a stoma. Duncan Wells wrote an article in *Tidings* Winter 2015 outlining that the best thing an ostomate can do is not draw attention to themselves. You do not have to tell anyone you have a stoma and there is no need to act any differently to before. You may like to carry a **Colostomy Association** travel certificate and a copy of your repeat prescription in case of any questions but the chances are you will be through as quick as anyone else.

Many worry about the body scanner and until last year I had never encountered one. I don't know if they are becoming more common or it was the airports I used, but I was scanned four times last year. The first time, out of interest I asked the lady about stomas, explaining I was a **Colostomy Association** trustee. She took the time to show me the digital image which showed a yellow square in the area of my stoma. If a square box comes up you may then be frisked but this takes all of 10 seconds and if you say you have a medical device it explains the yellow box they are seeing on the screen. The other three occasions I said nothing and airport staff said nothing so I went on my way.

I had a sacral nerve implant a few years ago and was advised not to go through the metal detector so they used a wand version. My jeans zip set it off which lead to a quick frisk. They felt my hernia lump so I mentioned I was wearing a medical device. As the scanner had beeped and I had a "lump" they asked if I would go to another room. It took no more than 2 minutes and all I had to do was give them a glimpse of the bag. They were very professional but also very reassuring so I would honestly say don't worry if this were to happen to you. You will not be the first and certainly not the last ostomate they see. This isn't something that happens every day though so no need to worry. Normally I wander through security more concerned about getting a coffee and a pastry at the other side than my bag!

So you've made it through security and hopefully not spent all your holiday funds in duty free. Next comes the flight itself. We have all heard stories of colostomy bags blowing up like balloons when flying but although everyone produces more gas due to the change in pressure, as long as you have a working filter on your bag there will be no problem. The idea of changing a bag in a tiny aeroplane loo can be worrying too. Many people ask if they should just stop eating before they fly but this can lead to more problems so we advise that a few days prior to travelling you stick to foods you know agree with you so upsets are unlikely. But having changed a baby's nappy in one of those loos I think me and my bag would be fine! I might take an air freshener to spray when I'm done, but you know what, everyone's poo smells so I wouldn't worry too much.

We are now at our destination, whether we have flown, travelled by car, train or ferry. If you are staying in a hotel or B&B you may worry about disposing of used bags, but they can simply be placed in your usual disposal bag and placed in the bin in the bathroom. The cleaners will take them away as with other rubbish. If you are concerned about leaks you may like to take a few disposable bed pads just in case, but if you do leak on the bed please don't worry – the staff will have seen it all before.

If you want to swim, the stoma should not stop you. Colostomy pouches these days are discrete and cannot be detected beneath a swimsuit, especially if it is patterned. However, if you are concerned about this, most manufacturers make mini–bags, so it is worth contacting them to see if they make a smaller version of the one you are currently using. Stoma caps cannot be seen beneath the skimpiest of swimwear. If the filter on your stoma bag gets wet, this can cause it to become blocked later on. To keep it dry cover it with one of the sticky patches, now provided in all boxes of appliances, before getting into the water.

All that remains is to relax and enjoy your trip. Travelling may require a little more planning than before but having a stoma should not stop you enjoying time away from home.

Sarah Squire

Travel Certificate
for people with
a colostomy

24 Hour Helpline
0800 328 4257
TOLL FREE FROM THE UK ONLY
International: +44 118 939 1537
OFFICE HOURS ONLY

colostomy association

www.colostomyassociation.org.uk

Never travel without your Travel Certificate

The **Colostomy Association** travel certificate explains that the holder has had a surgical operation which makes it necessary to wear a pouch to collect body waste and also has to carry spare supplies in carry–on luggage. This is translated in 15 different languages: Arabic, Croatian, French, German, Greek, Hindi, Italian, Mandarin, Polish, Portuguese, Russian, Spanish, Thai, Turkish and Vietnamese, so it can be used all around the world.

It includes a form which has to be completed with the holder's details including passport number and doctor's name and address. Then it has to be countersigned by the doctor or stoma care nurse and include the practice stamp. If you remember to ask your doctor to sign it during a consultation, you may not get charged for this service.

This certificate is to explain the purpose of a pouch to security staff at airports should it be detected during a body search or body scan. Therefore make sure you have it in your hand or your pocket as you go through security, not in your handbag or carry–on luggage which will be on the conveyor belt.

Two *Tidings* readers found that their travel certificate can also be useful in other situations.

- **Nancy writes:** Earlier this month I was travelling back from Tenerife by plane. I had carefully put all that I needed for my stoma in my hand baggage. My plan was to change at the airport between check–in and the call to the departure gate. When I took my luggage to the check–in the assistant insisted I needed to let her put my hand luggage (and that of my husband) through with my luggage for the hold although it had been clearly marked by another assistant as hand luggage. When I got to the other side I asked for it and was told it would be returned to me at security. They knew nothing about it and told me to find the person who had taken it, not easy as I was in a wheelchair. We continued to ask various staff and got no help.

  By this time I was getting worried as I needed to change. In desperation I went to the information desk with my certificate opened to Portuguese. Immediately the lady there was on the phone and someone else was called, there was a buzz of activity eventually someone came to tell me that they were searching the hold for my bag. Next I was told they had found it and they would hand it to me as I boarded (there being no time to bring it to me).

  On arriving on the plane I discovered that they had found my husband's bag not mine. The officer in charge of the cabin assured me they would find mine before we took off and offered to call me a doctor, which I did not need. Was I relieved to eventually see my bag. I was then taken to the toilet at the front and told I could use it although we were not in the air. We were moved to club class seats and I was given a cup of tea. Not a journey to be repeated...

  ..I could not get anyone to take notice until I produced my Certificate!

- **Laura,** who visited the **Colostomy Association** stand at an Open Day organised by the stoma care department of Peterborough City Hospital told us that her travel certificate came in very useful when she was on holiday in France with her husband and children. They were on an exchange visit staying with a French family. She showed them the French translation explaining what a colostomy is so that were aware of her needs when irrigating and understood why she would take a little longer in the bathroom. ■

Traveller's Tip

If travelling with a partner, include half your stoma and/or medical supplies in your luggage and half in theirs. Some travellers do the same with their clothes!

Your Travel Checklist

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

The ostomate needs to remember to:

☐ pack sufficient supplies for your stay;

☐ take all supplies and travel stoma kit as hand luggage;

☐ ask the airline in advance if you need extra hand baggage for your supplies;

☐ 'check in' online 24 hours before departure to secure your preferred seat;

☐ avoid food and drink that are likely to cause upset or excessive wind the day before you travel;

☐ pack all your normal medications and any that may help an upset stomach;

☐ carry your Travel Certificate with you especially when passing through immigration or security areas;

☐ pack some form of electrolyte replacement solution in case you become dehydrated;

☐ drink bottled water, avoid ice in drinks and use boiled or bottled water to clean around your stoma in countries where water could be contaminated; and

☐ store your supplies in a cool place, out of direct sunlight.

CA Booklets, Leaflets and Factsheets are available

Simply contact:

General Enquiries:
0118 939 1537

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

or

E-mail:
cass@colostomyassociation.org.uk

or download from our

Website:
www. colostomyassociation.org.uk

Living life to the Full

The photograph, above, was taken in Zante, Greece in 2010, the first time I wore a bikini after having a stoma. Since then I have travelled extensively to Spain, Majorca, Menorca, Greece, Cape Verde and Africa.

My husband, Ian, comes from Guernsey and we regularly go over there to visit all his family. And yes I always wear a bikini on the beach. I am also a Karate Sensei (instructor) and this summer learnt to ride a motorbike and took my Compulsory Basic Training. So you could say having Inflammatory Bowel Disease (IBD) and a stoma has not stopped me, it has spurred me on and made me live my life to the full.

I first became ill with weight loss, fever, sickness and chronic stomach pains in January 2009.

In March I was admitted to hospital and was put on a drip and treated with steroids. I made some improvement and was discharged 10 days later, only to be rushed back in to hospital the very next day, very poorly and suffering from the bacterial infection Clostridium difficile. After seven days in isolation I appeared to get a little better then in the middle of the night on 30 April, my wedding anniversary, my stomach became very distended and painful. My bowel had perforated.

When I awoke two days later in the High Dependency Unit I was given the very surprising news that I'd had most of my large bowel removed and now had an ileostomy and would have to wear a stoma bag. Still under the influence of so many drugs, I told the nurse that they had the wrong person as I did karate and had a six–pack and it would not look right.

After being so poorly and off work for such a long period having a stoma did not really bother me, because I began to feel better and regain my strength. It did not actually take me very long to accept and get used to life with a stoma, although I had quite a few accidents with the flange not sticking to my skin and the bag leaking. Because I am of slim build the stoma nurse suggested a convex bag which had a firmer more secure fit and I have used this ever since.

I returned to work at Bolton social services as a contact officer in child protection, a very challenging job. My manager and work colleagues were extremely supportive and made changes to my role to ensure I could work effectively as part of the team. Without this support I doubt I would have gone back to the job I loved.

After surgery I also went back to my Karate club – I am a black belt and very proud of it. The other members know about my stoma and are all very kind and do not treat me any differently. Sensi Michelle, the founder of Chi Chuan in Radcliffe has been amazing, visiting me in hospital and making sure I never gave up. I now hold the rank of 3rd Dan and work as a voluntary Karate instructor twice a week.

My family have been a great source of support especially my husband, Ian. He has been my hero; not once was he fazed with the many challenges and obstacles that I came across whilst learning to cope with my stoma. We have been foster carers for the local authority for many years and I am now involved in training new carers. My husband and I foster young people on a long term basis and we currently have a 16 year old and a 13 year old who are very lively and energetic. While this can be challenging at times, the boys are a useful distraction as they keep us both active and entertained. The boys have been very loving and caring particularly admission with a twisted bowel and they now realise that while people look fine on the outside, they can be sick on the inside. On a recent beach holiday one of the boys spotted another lady wearing a bag so we acknowledged each other with a smile.

My stoma has not affected my life for the worse but there are certain things I do differently, for instance I would not eat a meal then take my bag off to shower as it would be very active. I find that my stoma can make noises so I tend not to eat if going into a meeting. I still wear tight clothes and jeans but the waist band has to sit just above the stoma. From the start of my illness in 2009 my husband has been a constant source of love, support and encouragement as has my sister, Jacqueline, (who thankfully obtained my first copy of Tidings, which I have kept ever since) and the rest of my amazing family and friends.

A couple of tips to pass onto fellow 'Stomys' if going on holiday, I always check with the airline welfare department and request a seat near the toilet and an extra cabin luggage allowance for bags, extra clothes etc. and I have always been granted this at no extra cost. If staying in a villa I always ask for the en-suite room. Once on holiday I am very careful with food and drink not over doing it and sticking to what I know I can digest.

I love to travel and wear a bikini on the beach. I do not let my stoma stop me doing this; in fact I am quite proud of my stoma and happy to share my stoma story.

Crisi Taylor

Editor's Note

The ***Colostomy Association*** *understands that not everyone adapts so well after surgery and it can take a while to adjust to living with a stoma. Our 24–hour helpline and our closed Facebook group are ideal ways of supporting you through this life changing surgery.* ■

Travel Insurance...
..Your Question Answered

Q: What criteria do insurance companies consider when calculating travel insurance premiums?

A:
- *Age of person(s) to be insured*
- *The level of cover required*
- *Countries to be visited*
- *The period of the travel, whether it's an annual multi–trip or a single trip*
- *Any pre–existing medical conditions*
- *Extensions in cover required ie winter sports, hazardous/sporting activities, gadget cover*

Q: How and why does having a stoma affect travel insurance premium?

A: *A stoma itself has little to no effect. The insurers, however, need to know the type of stoma and, more importantly, the reason why one has a stoma, as this may affect the premium.*

Answers can include:
- *bowel/anal/rectal cancer;*
- *Crohn's disease;*
- *diverticulitis;*
- *bowel perforation or as a result of internal injuries suffered in a car/motor cycle accident; or*
- *an accident at work.*

Q: How soon after surgery is it possible to obtain travel insurance?

A: *This depends on the type of surgery and relevant recovery period. Insurers ask if the surgery was less than six weeks ago, six to 12 weeks or over 12 weeks and then quote accordingly.*

Q: What is a pre–existing health condition?

A: *An illness or diagnosed condition for which you have received advice, or you have experienced symptoms or received treatment. Different insurers will have their own list of conditions they need to be informed about before you travel so you should always pay close attention to the insurers' medical warranty.*

Q: I have had a stoma for a few years now and have never had a problem with it. Do I still have to inform my insurance company?

A: It is advisable to do so but often depends on the insurers' medical declaration requirements. If you have a stoma then you will be having prescriptions on a regular basis for the bags and other supplies, so the likelihood is that it would have to be declared.

Q: Are follow–up appointments and routine colonoscopies regarded as ongoing treatment?

A: No – these are check-ups following surgery/treatment. An example of ongoing treatment is radiotherapy or chemotherapy. If you are on a waiting list for treatment or investigation you will need to make your insurer aware.

Q: If stoma surgery occurs during a period covered by annual travel insurance is it necessary to inform the insurance company?

A: Yes – This is a material fact and any changes to the medical declaration during the period of insurance must be advised so insurers can reassess the risk and charge an additional premium if deemed necessary or in extreme cases refuse to continue your cover.

Q: Is it advisable for holders of a European Health Insurance Card (EHIC) to travel in the EU without travel insurance?

A: No – However, sometimes the EHIC is the only available option as a full blown travel policy may be too costly due to the proposer's medical history and other factors. The EHIC does not provide cancellation and curtailment cover or repatriation expenses (the costs of getting you home – in the worst cases this may involve the hire of a private medical aircraft to fly you home). Also cover does not apply if taken ill in international waters i.e. on a cruise ship. All travellers relying on the EHIC should check the exact cover provided as they can vary – treatment is usually limited to state hospitals and some insurers will waive the excess if a portion of the medical emergency costs have been recovered by insurers.

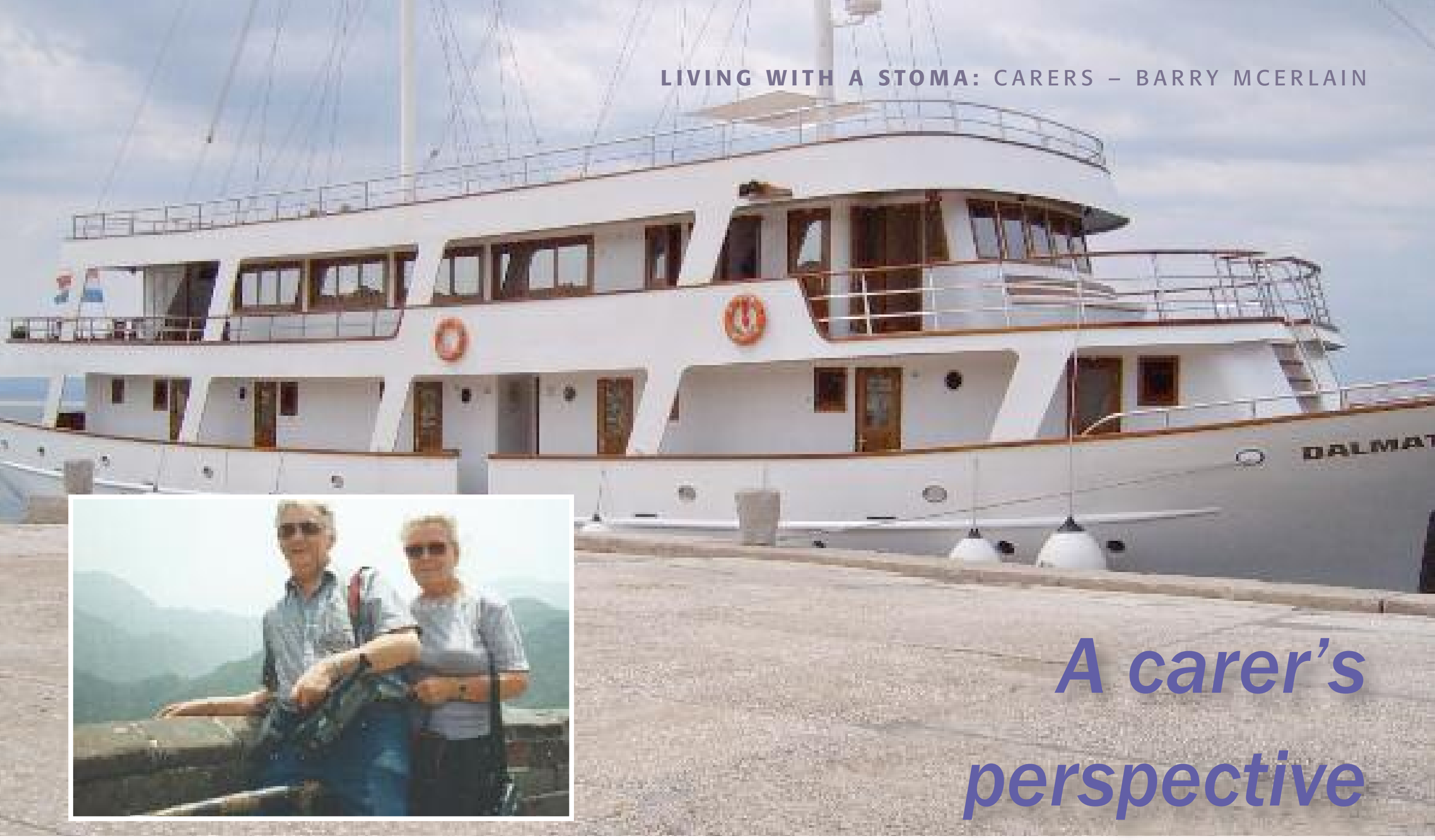
Q: If stoma supplies are stolen or lost does travel insurance cover the cost of sending out further supplies?

A: The cost of replacement is covered subject to the policy excess but the cost of sending out supplies is usually not covered. However, if you are able to source supplies in the country you are visiting and purchase such items, as long as a receipt is produced then the cost can be reimbursed once you return home. The CA can give advice on such suppliers in the countries you are visiting.

Peter Martin A.C.I.I.
Chartered Practitioner
Bournemouth Insurance Group

Remember:
- it is important to obtain alternative travel insurance quotations and compare on a like for like basis, so you can make an informed decision as to which insurer to use;
- to check the limits of cover and the level of excesses applying;
- to take a note of important contact details in case of a serious emergency as well as a note of the policy number and the insurer;
- to check the policy cover and documentation to make sure they are in order and meet with your requirements;
- to read the claims procedures and note what information is needed to support a claim;
- it is often wise to carry additional supplies of your regular prescribed medications in your hand luggage in case your bags are delayed; and
- the cheapest policy may not always be the best.

A carer's perspective



Inset: Dian & Mack on the Great Wall of China

Above: MV Dalmatia "We can manage on a small ship like this so a large cruise liner or hotel room is no problem at all"

You may remember in the last issue Mack shared his experience of supporting and caring for his wife, Dian. In his second article Mack considers going to stay with friends and relatives as well as holidaying abroad.

At some point you may want to go and stay with friends or relatives, but the person with the stoma may be very reluctant. This is not because they just want something that is bit more pampered and special.

As a carer/partner I am aware that my wife is a little bit nervous about a pouch leaking in somebody else's bed. No matter how much reassurance I give her, the fear remains, despite the fact that we have been on holiday many, many times and there has never been a problem. However, what we tend to do now is tell relatives we are taking the opportunity to do some touring in and around, but we will call in to catch up on old times. Then we play it by ear and, if necessary, stay in a hotel, or boarding house. We always take cot–sized bed protection which allows my wife to sleep a little easier.

Then there is the question of if or how you tell others about the stoma. Our view was that it was better coming from me, the carer/husband. Although I am closely involved, it is not me with the stoma and as such I am able to be a little bit detached. Most friends and relatives were aware that Dian had to be admitted to hospital, and asked how she was and what had been the problem, so the subject was simple to bring up and we just answered their questions as honestly and frankly as possible. Most people had some idea what a colostomy was even if they did not know the full implications. One acquaintance did not quite understand as she asked if my wife had to go to the hospital every year to have her pouch emptied!

Going abroad has not proved a problem; we often travel with Saga, and their insurance is very acceptable. They know all about Dian's colostomy and have not placed any restrictions or excesses on our policies because of it. However, I must point out Dian's procedure was as a result of diverticulitis and not cancer. We have used Staysure and Global insurance and when we took a cruise holiday with Thompsons we went through their own insurance screening, all without any problems.

As mentioned in the last issue of *Tidings*, some suppliers will send supplies abroad. We thought we would give this a try. Five days after they arrived in the country, we were informed that the supplies were waiting at customs at the main airport. We had to go in person and pay €100 import duty before they would be released; this was in Croatia, a country within the EU. So the lesson is to make sure you take sufficient supplies, and a few more, just in case unusual foods or spices affect the regularity of the stoma output, or you experience an unexpected delay.

When our holiday involves a flight, we approach the airline a couple of weeks prior to the flight and explain that we would appreciate being allowed to have one more small piece of hand luggage of about 4kg in weight, to accommodate essential medical dressings. They normally ask for a letter from the hospital to confirm the necessity of having this equipment with us, and not in the hold baggage. Most airlines, BA, easyJet, KLM, Virgin and Jet2 have all been very accommodating. Monarch keep their records of our application on permanent file so we don't have to keep asking.

Whatever you do, do not let the stoma put you off flying to faraway places. Dian had her stoma in 2008 and since then we have been on holiday a number of times every year. We have stayed in hotels in the Isle of Wight and Jersey, visited China and the USA. We have even sailed the Adriatic aboard the 28 berth MV Dalmatia and visited ports and small islands on the Croatian coast. All that's required is a little bit of additional planning, and the will to not let a stoma spoil our life.

Bon Voyage

Mack

Do you support or care for someone with a colostomy? If you would like to contribute to our *Carers' Column:*

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

The Editor
Colostomy Association
Enterprise House
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Colostomy Association launches two new pilot schemes

Getting Active

Since the beginning of the year the Colostomy Association has helped people living with a stoma get more active again through a series of pilot workshops in Berkshire.

The **Colostomy Association** delivered a series of workshops in support groups across Berkshire aimed at getting ostomates on their feet and active. Attendees were encouraged to get moving through specialist chair yoga sessions that met the needs and abilities of those on the course.

Although having a stoma is no limitation to living an active life, many adults and children find it difficult to take part in activities particularly after stoma surgery.

A **Colostomy Association** spokesperson said: "We believe that having a stoma should not limit people from living a full and active life, but some ostomates do need a little bit of additional support to help them become more confident about exercise and fitness.

"The response to our pilot *Active Ostomate* sessions in Berkshire has been incredibly positive and we hope to launch the scheme in other parts of the UK."

The **Colostomy Association's** Active Ostomate workshops were funded by Sport England and Berkshire Community Foundation.

Based on the success of these pilot workshops, the **Colostomy Association** is now gathering the evidence needed to compose compelling applications for wider funding. This will enable us to run more sessions in other parts of the UK to make sure that many more ostomates become and stay more active.

In addition to the workshops, the **Colostomy Association** has also produced a new free booklet with information and advice for ostomates looking to stay active or to try out a new sport – more details on our booklet can be found on page 29 in this issue of *Tidings* and can also be downloaded from our website. ■

Improving the knowledge and skills of carers

Carers in Berkshire have received a boost in their knowledge and skills thanks to a pilot training scheme from the Colostomy Association.

Dozens of carers have taken part in one–day training sessions held across Berkshire. Run by a professional stoma care nurse, carers received up to date advice and information to ensure they are able to properly look after people living with a stoma.

The **Colostomy Association** has launched the pilot scheme to ensure that adults and children receive a good level of care. Research from the charity has revealed a lack of knowledge and training among many individuals caring for ostomates.

The training sessions were not only attended by friends and family of ostomates, but care homes and agency staff to ensure those most in need are receiving the quality of care they are entitled to.

A spokesperson for the **Colostomy Association** said: "Carers are vital in making sure that people are given the right sort of assistance they need on a day to day basis. Therefore it is essential that they have the proper training and knowledge to support those in their care.

"The pilot scheme for our *Caring for Colostomates* course has been incredibly successful and we are working hard to ensure that professional and unpaid carers across the UK will soon benefit from the **Colostomy Association's** information and advice."

This pilot project has been funded by The Big Lottery Fund and additional funding is currently being sought to bring the carers training course to other parts of the country.

The **Colostomy Association** also provides a *Caring for Colostomates* booklet which is available without cost on request. Please contact the **Colostomy Association** if you would like a copy or download this booklet from our website.

Look out for future updates and photos of these two pilot projects in a future edition! ■

From One Ostomate to Another

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

Three **Colostomy Association** volunteers answer questions about taking up sporting activities.

Gliding

I am 68 years old having had a stoma for three years and am coping very well with no on–going issues. I have always had a desire to try gliding and have recently visited a local club.

They inform me that the cabins on the gliders are not pressurised and I wonder if this will cause leakage problems because of increasing pressure differentials between internal abdominal and lowering cabin pressure the higher the flight goes. The club assures me that flights are "not very high" (whatever that means). I currently use a one piece drainable pouch and seek your advice on any possible problems and their solutions as I am determined to "give it a go".

Stephan Willers

Paul Foulger, Colostomy Association volunteer, replies:

I have been gliding since 1995 and thoroughly enjoy the sport and am sure that you will too. I had my stoma formed in 2001 and at the time it was thought that I may have to have two! However, I finished up with just a colostomy. As a glider pilot I thought that this would get rid of one problem when being in the air, in that I would not have to land because of the need of a loo!

You have had your stoma for three years now and I guess there have perhaps been a few problems at the outset but all have settled now; that being so, I do not think that you should have any problems at all by flying with a stoma. We do trial lessons at our club and I doubt very much that the heights reached would be any more than 1.219km (4000ft) maximum, and dependant on the type of lesson you are having they usually last between 10 minutes to an hour.

Since my stoma was formed I have never had any leakage problems or any other effects from the flying experience, so go ahead and enjoy - by the way it is very easy to get hooked on flying a glider as happened to both my wife and myself way back in 1995.

Regards and Happy flying
Paul Foulger

Cycling

In May 2014 I had APeR surgery and a permanent colostomy for rectal cancer. The perineal wound took a long time to heal fully (seven months), and even now is still very tender, and sitting for long periods can be quite uncomfortable. I would like to try cycling again, and after doing some research on the internet thought that perhaps the Rido R2 saddle might be suitable. However, after trying an ordinary saddle for a short distance, the discomfort I felt seemed to come from the buttocks (presumably because I have rather less padding there than I had before surgery) rather than the perineal area, so perhaps a well–padded normal saddle would be better. I just wondered if any readers had any experience of cycling after APeR surgery, and might have some observations or advice to offer.

Regards
A.M.

Ian Jackson, Colostomy Association volunteer & Trustee, replies:

I had my APeR surgery in autumn 2011 and after a couple of false starts managed to get back to cycling in the autumn of 2014. I started off on a town hybrid bike that has a little suspension and quite a broad padded saddle. By spring 2015 I was able to get back to riding a road bike with a very thin saddle. Although I'd always said I'd never become a Lycra–wearing cyclist I do find the padding in cycle shorts and leggings really does help so now wear them for all my long rides. I think my advice would be to try different saddles and even bikes, if you can, to find something that best suits you now, then start off with short rides and build up

CONTINUED ON PAGE 45, COLUMN 1

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Colostomy Association

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CONTINUED FROM PAGE 43, COLUMN 3

to longer rides. It did seem to take me a long time to get back to cycling but I'm glad I stuck with it.

All the best of luck to you. I hope you're (comfortably) back in the saddle soon.

Ian Jackson

Skiing

Do you know anyone with a stoma who goes skiing?

Helpline Caller

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

editor@colostomyassociation.org.uk

Robin Mills, Colostomy Association volunteer, replies:

Skiing with a colostomy pouch has its advantages and disadvantages, none of them life–threatening but there are some quite challenging complications. The one advantage, of course, is the fact that you cannot really be caught short, as they say.

Ordinary skiers have a great fear of being stricken like this. There are no bushes on the best ski slopes, so the only thing is to head at speed for the nearest loo and hope that there is not a queue. Mountain restaurants do not have disabled facilities. With the thick warm clothing that is often necessary, accessing the stoma can be a major operation. Snow from boots usually makes toilet floors wet so you have to be careful not to drop anything. There may, or may not, be a hook long enough to hang more than one garment. Ski suits with a zip down the front keep trousers off the floor, However they are difficult to handle if you get too hot.

Of course if you can irrigate successfully before venturing forth you will have a carefree day. I imagine the plug might work, although failure would be too dire to risk. The next best thing is a drainable pouch which is not difficult to empty and may not need attention until you return at the end of the day. However, make sure you have a filter that works as if the pouch balloons falling forwards could blow the seal.

In one chalet I could not understand why everyone else knew what was going on. When I asked the chalet girl, I discovered she was posting notices on the lavatory door where the others could easily see them. She looked really puzzled to hear that I never looked there.

I am not a good skier but I love the mountains, the atmosphere, and the ability to enjoy both the thrills, and spills, that you get from skiing. I managed 24 years with a colostomy and only stopped at 84 because I thought I would not be able get up if I fell.

Robin Mills

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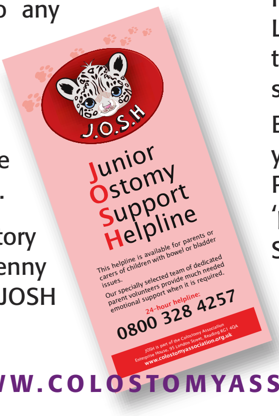
Junior Ostomy Support Helpline (JOSH)

L–R: Laura and Jennifer

Many of our readers will be aware that the Junior Ostomy Support Helpline (JOSH) is managed by a team of volunteer parents ready to answer any questions that a carer or parent of a young ostomate may have.

However, two of our volunteers have had stomas themselves – both lived with temporary stomas when they were younger and currently live with ileo–anal pouches. Laura and Jennifer can not only speak to parents but also any young callers who would like to speak to someone who has been through the same experiences as them.

Find out about the story of how Laura and Jenny both became JOSH volunteers:



J.O.S.H

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Ostomy
Support
Helpline

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Our specially selected team of dedicated parent volunteers provide much needed emotional support when it is required.

24-hour helpline:
0800 328 4257

JOSH is part of the Colostomy Association
Enterprise House, 95 London Street, Reading RG1 4QA
www.colostomyassociation.org.uk

2 sisters, 0 colons

Our journey to becoming JOSH volunteers began in the year 2000 when at the age of 12, Jennifer had her colon removed as a result of Ulcerative Colitis and later went on to have surgery to create an Ileo–Anal Pouch. Fast forward to 2013 and older sister Laura also underwent surgery to remove her colon, having been diagnosed with Ulcerative Colitis five years previously. Following a year living with an ileostomy, Laura had surgery to create her pouch at the age of 30. This is how we became 2 sisters with 0 colons.

Between the two of us, we now have 15 years' experience of living with an Ileo–Anal Pouch and we are yet to meet any other 'pouch siblings'.

Shortly following Laura's final surgery, we met **Colostomy Association** trustee Wendy Hetherington at an event hosted by the stoma care team at our local hospital. Amazed at meeting sisters who both had pouches, Wendy asked if we would be interested in becoming volunteers for JOSH.

We were both keen to get involved and thought it would be a great opportunity to help others going through a similar experience which can often feel very isolating. Having spoken to other pouch patients during our own surgeries, it's now great being able to volunteer with JOSH so we can listen and support junior patients or their parents.

The helpline training provided by JOSH has been brilliant and has allowed us to meet fellow helpline volunteers. ■

Do you feel you could benefit from speaking to Jenny, Laura or any of the other JOSH helpliners? Then please call **0800 328 4257** and ask to speak to a JOSH parent today.

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Facebook Group

CA Facebook are go…

It's been a busy few months on the CA Facebook support group. Membership continues to grow, mini meets are taking place across the country and we are trying to organise a couple of official group meets in the next year or so.

As always, our members help each other whenever they can and a true example of group members coming to the rescue was seen when admin Steve Clark helped a member in need while on holiday in Spain. Steve writes:

> "My wife, Cherry, and I were in Spain, visiting my sister, who lives in Javea on the Costa Blanca. We had a glorious week, except for the Thursday, when it was raining but it didn't stop me from going in the swimming pool; I was already wet so what did it matter?
>
> "To finish our week we had a family night at a local restaurant on the Friday. We had an early start on Sunday morning to travel home, so a Saturday shindig was not really advisable.
>
> "On Saturday morning, I checked the CA Facebook group feed and noticed a post that went something like "Help….Panic…I have run out of pouches!" Then came the punchline: 'Is anyone in Benidorm?' Well, we were about 40–45 minutes away by car so I replied to the post to that effect. Unfortunately, on a package deal in Benidorm, they had no transport. OK, plan B – we are leaving from Alicante Airport on Sunday so could pass through Benidorm at about 7–8am in the morning. Details were finalised and we reset our alarm for an hour earlier!
>
> "We were quite pleased not to have to use the 'motorway' from Javea to Alicante, taking the more scenic and, in parts, beautiful coast road to Benidorm. Eventually, we found the right hotel and made contact with our unfortunate friend in need of the pouches. Not a nice time of day to get up when you're on holiday but needs must. We adjourned to a local bar… ..at 8am on a Sunday morning! Coffee, tea and vodka came very quickly and we had a very convivial half hour before we had to take our leave and get to the airport. Although this was my first flight abroad since my surgery, I have got into the habit of always taking plenty of spare supplies with me when I go away. Disasters can happen to me in terms of upset tummy, lost luggage or any number of other possibilities. In this case, I was delighted to be able to help a fellow colostomate in distress."

The CA facebook group really is more than just a place to find answers to stoma problems. It has become a family, where members will do everything they can to help each other, where they become firm friends and can share experiences good as well as bad.

A few weeks ago a member had the idea to post their photo – to put a face to their name. Many people have a cartoon, or photo of a pet or family as their profile picture. This may of course be a conscious choice to remain anonymous which is absolutely fine but once one person had posted a picture the response was incredible. Literally hundreds of photos followed as the *face to name* idea grew. Members new, old and those who have never posted before started putting photos onto the group. It really lifted the spirits of many, and even encouraged our own Ian Daniels, president of the CA to comment, praising the photos of ostomates living a normal life. He said: "Congratulations, it's inspirational for those who are about to undergo surgery and fear life with a Stoma, so well done". Group member Shelley Lawes took it a step further by suggesting people donate money to the **Colostomy Association** when they post their picture. She set up a *JustGiving* page and at the time of writing, the amount raised was close to £200. So not only did members come together by sharing photos, they also turned this into a fundraiser for the **Colostomy Association.** I feel privileged to be part of such an amazing group!

Sara Squire

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

Colostomy Association Facebook Group hits 4,000 members

The Colostomy Association's Facebook Support Group has hit a new milestone as it reaches 4,000 members.

The Facebook Support Group is a safe, welcoming online space where people with a stoma are able to share advice, tips and information with each other. As a 'closed' group, posts can only be seen by other members of the group which ensures members can feel that anything they post will be safe and confidential.

The **Colostomy Association** set up the closed Facebook group six years ago in September 2009 as the charity felt an online support service was needed for ostomates across the UK.

Within two years, the group had 500 members and today more than 4,000 ostomates use the group as a source of advice and support.

Although it may be hard to notice, a lot of work goes into managing and moderating the Facebook group. A team of trained Facebook admins ensure that abusive comments are deleted, that advice given is correct and that the group remains a welcoming space. All information provided is based on experience and no medical advice is provided.

Sarah Squire, **Colostomy Association** Trustee and Facebook Group administrator said:

"It is fantastic to see the Facebook Support Group reach 4,000 members – our group benefits from the collective information and knowledge of our members.

"The advice in the group is fast and thorough – people can have answers to problems literally in minutes, and as we have a lot of international members as our advice is 24–hours a day."

Want to help us hit our next milestone of 5,000 members? Search for 'Colostomy Association Support Group' on Facebook and register to become a member of a fast–growing community. ■

JOSH receives PSNG Paediatric Stoma Nurse Group endorsement

The **Colostomy Association's** dedicated helpline for parents and carers of children with bowel dysfunctions – JOSH – has received the endorsement of the Paediatric Stoma Nurse Group.

The Junior Ostomy Support Helpline was launched by the **Colostomy Association** at the end of 2014 to provide a much–needed service for parents and carers of children with a variety of bowel dysfunctions and diversions. JOSH has now received the support of the UK's main association for stoma care nurses who work with children.

The endorsement underscores the need for a service like JOSH. Any callers to the helpline can arrange to be called back by a fellow parent or carer or a child with a stoma. Callers can be matched with helpliners whose situation closest mirrors their own. Our helpliners are then able to provide practical and emotional support.

The Paediatric Stoma Nurse Group was established in 2005 and has developed into a valuable, proactive independent forum, working closely with industry in research and development.

Speaking about the endorsement, **Colostomy Association** trustee, Wendy Hetherington, said:

"We are incredibly proud to receive support from the PSNG who perform wonderful work for children with a stoma across the UK.

"The endorsement demonstrates the quality of support our helpline can provide to parents and carers who may be struggling to bring up a child living with a stoma."

If you would like to speak to a JOSH helpliner then call **0800 328 4257** and request a JOSH parent to give you a call back. ■

The breakaway Foundation

Celebrating 10 years The Breakaway Foundation

One of the Breakaway families first found out about Breakaway through reading *Tidings,* here they tell us what Breakaway means to them.

"I brought in a very withdrawn, scared and sad child on the Friday afternoon and I brought back home a lively, confident and empowered child on the Monday. That is the magic Breakaway creates with its magic wand! The wonderful opportunity for my daughter to see with her own eyes for herself that she was NOT the only child with a stoma meant she could drop the huge pressure she was making herself feel she had to be under all the time because, for once, she was not different. She did not have to worry about people judging her… she did not need to worry about her bag showing, about her stoma making funny noises or smells or about feeling down about her condition. It was a life–changing experience for me too as all of sudden I could word out any worry, concern or battle I was going through knowing someone would understand me and not judge me, however crazy my questions were, and maybe even help me. We now have friends for life and when going through tough times, we have the knowledge that we can just pick up the phone or meet up with friends who will not look at us like aliens. And that is the amazing gift Breakaway has given us and for which we are eternally grateful! Wonderful staff, lovely locations, superb food and amazing people! What is there not to like about Breakaway? That, as my daughter said, it has not created its own school yet so all children with bowel diversions could be their usual selves without fearing judgement! That comment says it all! Thank you, thank you, thank you!"

Want to help us celebrate our tenth birthday?

10 Year Anniversary Gala Dinner on Saturday 7th May at the National Brewery Centre in Burton on Trent. £40 per person, includes 3 course meal and wine. To buy tickets, please email us.

10th Birthday Family Fun Day on Saturday 9th July at Beaumanor, Leicestershire. Activities may include craft, zip wire, high ropes, cannons, rocket building, bouldering, hide and seek in the cellars, and there will also be an exhibition from all the major stoma care manufacturers. Tickets are £5 a person and can be booked via the Eventbrite link on the Breakaway website.

August Family weekend, from the 26–29th August at the YHA National Forest in Moira, Derbyshire. Cost is £185 per person, which includes all meals, accommodation and activities. Funding may be available to those on a low income. Email us for a booking/funding form.

Sue Blackwell
Breakaway Trustee

More information about Breakaway Foundation.

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Dear Nurse

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

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

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

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

Q: *I have had a colostomy since 1997 and had little trouble with it. Recently I have had constipation even after eating fruit, and drinking fresh orange juice and plenty of water. Can you suggest anything else to relieve me of the constipation?*

A: Even with a colostomy you can suffer from constipation. You are doing all the correct things: increasing your fluid intake, eating fruit and vegetables and drinking fruit juices. If you are still struggling, you can also use laxatives such as Lactulose, Senna, Fybogel or Movicol and many others. It may be worth speaking to your GP for suggestions but do please continue with drinking plenty of fluids and a well–balanced diet.

Q: *Although I had my bowel operation nearly 10 years ago, about two years ago I started suffering with radiation cystitis due to the extreme amount of radiation I received. I had 33 sessions of radiotherapy which I believe is not the norm but the professionals at the time were trying to eradicate the tumour without surgery. However, it wasn't successful and ultimately I ended up with an end colostomy and rectal removal.*

My question is concerning the 'Radiation Cystitis'. Firstly I am interested to know whether, and to what degree, the radiation cystitis is likely to deteriorate. I have been told that it is gradually destroying the good tissue in the bladder hence the bleeding and clots. I cope with issues when I know what I am likely to face in future. I am not negative, in fact very positive. I do know that some sufferers end up with a urostomy due to this condition and wonder whether there is any particular time factor involved in the deterioration.

Also, another problem I am experiencing with the radiation cystitis is that I am given regular cystoscopies to ascertain the condition of the bladder. The first one I underwent was under general anaesthetic and I experienced no problems afterwards. However, the last two cystoscopies were performed under local anaesthetic and, although the actual procedure was completely painless, as soon as the local anaesthetic wore off I experienced excruciating burning pain which lasted more than two hours. The last time this happened I was admitted to hospital after the procedure and given intravenous painkillers. The professionals I believe are somewhat confused as to why this has happened. Obviously I am very dubious about having this procedure repeated. I am interested to know whether anyone has experienced the same reaction.

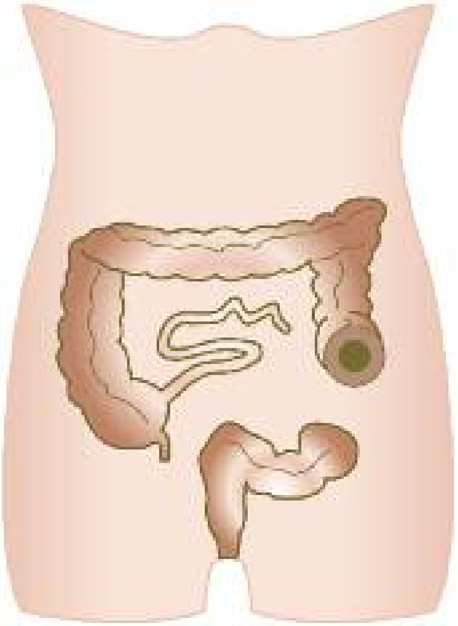
I look forward to receiving any feedback you can offer.

A: This is a very complex query and I have to admit I am probably not the most appropriate person to answer this. I would suggest sitting down with your consultant to see if they can give you any timescales with regard to the deterioration of the condition and the potential for surgery to remove the bladder if that is what you have been informed could be a solution. The regular cystoscopies will be undertaken to assess the condition of the bladder and the rate of deterioration which will ultimately direct the treatment plan and timescale. I can understand your concerns with regards to the planned cystoscopies in the future following your experience last time. I have to admit I am unsure as to why this should have occurred, possible trauma to the urinary system or infection may be a cause but I would hope that if your surgeons are aware of the problems they would have a plan in place to try to negate any similar problems in the future. I wish you well and am sorry I am unable to provide definitive answers to your queries.

Q: *In February 2015 I had polyps removed from my bowel which turned out to be cancerous. I then had an operation on my rectum called a Hartmann's and I am having a few problems with my stoma which my stoma nurse is sorting out for me.*

However, what I would like to know, please, is what in fact is a Hartmann's procedure operation and how is it done? Hope you can help me.

A: A Hartmann's Procedure can be performed either open (laparotomy) or through keyhole (laparoscopic) and involves the surgical removal of the sigmoid colon and upper rectum (the lower section of the large bowel) which is situated in the left hand side of the abdomen. The lower rectum is then oversewn and left in situ as a rectal stump and the descending colon is brought to the surface of the abdomen as an end colostomy. This can be performed for several reasons including cancer and diverticular disease. Some patients may find that they can have the stoma reversed but others are informed that it will be a permanent colostomy. ■



Hartmann's procedure

Reply to a letter about blockages caused by adhesions which appeared on the Dear Nurse page in the Winter issue of *Tidings*.

I experienced exactly the same about 18 months after my bowel surgery and after being admitted to hospital with blockages on a regular basis (around six times or so) and given exactly the same treatment, a very knowledgeable stoma nurse diagnosed sub–acute obstruction and said that I would benefit from a diet without fibre. Up until then I was having regular high fibre cereal in the mornings plus brown and multi–grain bread. All very much a NO, NO.

Also I was advised to peel all fruit, eat no fruit or vegetables containing seeds and to drink plenty of fluid. This absolutely worked and I have now been on the diet for seven years with no blockages which have required a hospital visit. I do occasionally realise I have eaten something which has caused a slight blockage but can normally clear this on my own by adopting nil by mouth and plenty of fluids for a day. I do hope this helps as I really believe it is the solution.

Julie Replies: *I am glad that you managed to obtain a definitive diagnosis of sub–acute obstruction, and yes you are correct that a change in diet can influence the obstructive symptoms. I would advise all patients who develop symptoms such as this to seek medical advice in the initial period to ascertain what the problem is, as self–diagnosis initially is inappropriate as the cause may be more serious. Once you are aware of the cause of the symptoms and are experienced with identifying them, as you are, then placing yourself on fluids only can often solve the problem. As with anything, sometimes it works for one patient but not for others but with medical support it is always worth trying different solutions. Thank you for your input. It is always good to get ideas from patients, who after all are the people who live with the stoma 24/7.* ■

Use of Additional Products

Many companies not only produce pouches for use by ostomates but also a wide variety of additional products.

These include such things as:

- Adhesive remover in the form of sprays or wipes. They help to ease the adhesive flange away from the skin without causing trauma.
- Seals in a variety of sizes and thicknesses. They help to smooth skin which has creases, to absorb fluid secreted from skin which is sore and wet, and are used to provide security.
- Paste which comes in a tube. It can be used to fill skin creases and 'moats' around the stoma which will help adhesion.
- Barrier film in the form of sprays, wipes or creams. They provide a protective barrier for those with sensitive or irritated skin.
- Deodorants which may be drops, gels or granules for use inside the pouch.
- Air Fresheners. These are used when emptying or changing the pouch to disguise the odour. Most patients find that using the usual air freshener in their bathrooms is often enough.
- Flange Extenders, which are adhesive strips. They are used around the flange so that the adhesive surface is increased in size to give added security.

Often these products i.e. adhesive remover or barrier wipes, flange extenders or pouch deodorants are given out as samples. However, as not all of these are essential or suitable for all patients, it is advisable to contact your stoma care nurse to see if there is a Clinical Need for the use of the product. ■

Editors Comment

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

If so, write in and tell us:

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

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

Readers' writes


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

A friend who has a colostomy passed your magazine on to me and suggested I should write to you about my grandmother.

My grandmother was born in 1898 and in 1932 after having a hysterectomy she was given doses of radium. Sadly the radium burned her bowel which resulted in having a colostomy on 19 October 1932 – I believe at Mount Vernon Hospital in Northwood. She was extremely ill but was eventually discharged from hospital on 15 December 1932 weighing only 40Kg (6st 4lbs). I know all this because I have her diaries!

There were no stoma bags in those days and she had to wear a surgical belt with a plastic cup to protect the stoma. She had a copious supply of clean rags to wear in case of accidents!

As a child – I was born in 1945 – I remember her having to wash out the stoma every day, syphoning water into her body to flush it out. She had to do this all through the war – air raid or no air raid.

I can remember her having to go to London regularly to be measured for her belt and a Dr Donaldson in Riding House Street features regularly in her diaries. Her last visit for an annual check–up was March 1956 at Charing Cross Hospital (then off The Strand, I believe). This had continued for 24 years. She could hardly believe the advent of the stoma pouch – possibly in the 1960s if I remember and to be told by her GP that the daily "wash out" was no longer required.

My grandmother died in 1987 at the age of 89 having had a colostomy for 55 years. In the 1930s I expect it was a very rare operation and my grandmother did well to survive a very real near death experience.

I am amazed at how common this operation is now as I know four people in my immediate area who live with a stoma. Obviously no one wants to have a condition which needs a colostomy but I felt that my grandmother's story might give heart to someone who is having trouble getting to grips with the situation.

Yours Sincerely
Linda Jackson

Dear Editor

I was very impressed with the article A Carer's Perspective in *Tidings* issue 40. My wife had a stoma about six years ago now, an emergency operation, so very unexpected. It was not due to cancer, but her large bowel had died due to lack of oxygen. So you can imagine the way she felt when she came around from the anaesthetic. It is not reversible so we both have had a lot of changes to endure.

Unfortunately she has been left with a massive hernia and has to wear a corset as well as a stoma pouch. Many people do not realise what a couple have to go through and your article at least made us realise we are not, after all, on our own.

In June 2015 my wife had a major blockage and had to have another emergency operation. If it was not for the expertise of the staff at Kings Mill Hospital she would not be here now. The blockages have now cleared, but my wife still has a four inch open wound on her stomach which is awaiting plastic surgery.

But *Hey Ho,* we both have got to keep our spirits up so don't think just because you have a stoma that's the end. It could be worse.

On behalf of my wife
Mr A Elliott

Dear Editor

I am an avid reader of the *Tidings* magazine. I was very interested in the article on Page 35 submitted by Mack and his wife Dian in your last issue. I agree entirely with Mack's comments since I am a carer for my wife. Unfortunately she had cancer problems four years ago which resulted in extensive surgery. It has left her with a urostomy, colostomy and a vaginal reconstruction which resulted in removing muscles from the legs to build up the body. She is now living a normal life but limited in walking which obviously means we have had to curtail our hobby of

Readers' writes

short/long distance hiking. We have now changed our life–style and holiday in UK cottages and visit various places.

The **Colostomy** and Urostomy Associations all mention that this type of surgery should not change your life and should not restrict your requirements such as holidays etc. But we are very restricted because in our experience there is no insurance company prepared to offer us any form of insurance for UK or abroad even though my wife is free of cancer as agreed by all the specialists. Maybe you can give us some advice in this direction. We have tried the insurance companies which were specified by the Macmillan nurses.

Regarding Mack's comments, he does not mention anything about the fear of the disease returning. I find this is one of the main problems you have to come to terms with and obviously try to rule out the problem. Have you found this is the situation regarding most other cancer patients?

John Manson

Yes, the fear of cancer coming back is very common and was highlighted in an article by Beating Bowel Cancer's specialist nurse in the autumn 2015 issue of Tidings *(P49). While treatment is ongoing it feels as if something is being done to stop or treat the cancer. However, when it is over it may feel that nothing is being done and the cancer could return. This is a very natural reaction. This fear and anxiety usually settles over time; not only does the worry usually lessen but also the actual risk.*

To speak to other people who experience similar feelings visit the charity's online forum at: ***www.beatingbowelcancer.org/forum*** *or for any other concerns about bowel cancer contact the Beating Bowel Cancer helpline on* ***020 8973 0011*** *or email* ***nurse@beatingbowelcancer.org***

Dear Editor

My wife is a member of your association, and I always look forward to reading *Tidings.* I was pleasantly surprised to see Mack's story about being his wife's carer.

I am in a similar position, although now taking a less active role as my wife has become more adept at managing her colostomy. However, I've always considered that carers are more or less a 'forgotten army', who save the NHS and social services considerable financial outlay, so I think media attention is always welcome, both on TV and in print!

Everything Mack has experienced, mirrors mine, and my heart goes out to those that are perhaps alone, or do not have a family member to assist, especially when adjusting to their new way of life.

I am also grateful to Diane, the specialist nurse, who has always listened to my queries/concerns, and offered advice, recognising that it has been a team effort by us all from day one.

So, thank you for publishing Mack's story!

Regards
AG

Dear Editor

I read your magazine from cover to cover and it has been more than helpful so I thought I would tell you why and send you a donation which I have intended to do for some time.

I started to see streaks of blood in the mucus being passed by the remaining piece of bowel left after my colostomy was formed due to bowel cancer. This was in February 2014. My cancer nurses felt it was normal and were not worried. Six months later at the autumn check–up still no concern.

However, by December it was much heavier and smelly and your magazine carried an article explaining that something could be done about it. I took the magazine to my doctor after Christmas but the first appointment she could get me at the hospital was 23 April. By now I was very worried about secondary cancer. After several months of biopsies and then an MRI scan in July 2015 (18 months of worry) I had an operation and a growth was removed. Fortunately it was not cancerous. I am waiting for a second operation to make sure all was removed.

No more mucus discharge, no more smell. Thank you *Tidings* Magazine. This may be of help to someone else so I felt I had to write to you for that reason also.

Yours sincerely
JO

Dear Editor

I just wanted to make contact to say how precious *Tidings* magazine has been to me, in particular the extremely useful articles recently about irrigation. Although I had excellent medical care, it was only after I discovered the association and the magazine just over a year ago that I found out about all sorts of things which my nurses had not told me about.

The result of this is that I have finally been allowed to start irrigation, and am finding it most helpful, especially in my working life. This would not have come about without your magazine.

Thank you all very much.

CG

Dear Editor

I read with interest James' story, You Only Live Twice. My own experience in 2008 was very similar, except that I was on a coach tour in America when I felt 'something go' in my lower stomach area. I experienced all the same symptoms as James, but managed to get home two days later, and went straight to the doctors. How I managed the plane journey from New York I don't know.

I was examined and given anti–spasmodic pills for IBS and a stomach upset. I survived another week, not eating or hardly moving, before my husband almost carried me back to the doctors. Fortunately a different young doctor realised I was seriously ill and sent me straight to A & E. This was a Friday. I had a CT scan on Saturday and finally had my operation on Sunday – six hours in surgery and four hours in recovery – before going back to the ward at midnight.

The surgeon informed me that he had saved my life and told me I had a diverticular abscess which had burst, causing perforation of my bowel and peritonitis. A large portion of my bowel had been removed and I only had a 4cm rectal stump left. Nevertheless I was determined right from the start that if a reversal was possible I would go for it. My surgeon told me he would review the situation later and see how I felt then. Luckily I managed my stoma very well, with relatively few problems, but I did not change my mind about trying for a reversal.

CONTINUED ON PAGE 57, COLUMN 1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Readers' writes

CONTINUED FROM PAGE 55, COLUMN 3

My surgeon said it would be very difficult in view of the short rectal stump remaining, but I was determined to go ahead, so he put me on the waiting list, and 17 months after my initial operation he successfully reversed the Hartmann's. I was told it would not be as traumatic as my last operation, and I would recover much quicker, as this time I went into hospital feeling well, and this proved to be correct. I was discharged after a week, thrilled that I no longer had a stoma, although I was aware of the problems that can occur after reversals. I think I have been fortunate that my need to visit the loo has only increased a little, due to not having much rectum left, but that is all.

I don't know if this is a common problem, but my main concern now is a large incisional hernia around the site of my stoma. In 2014 my surgeon again reluctantly cut me open to repair the hernia, but unfortunately he was unable to do so due to excessive adhesions caused by my previous surgery. I think, therefore, this is something I will have to live with.

However, I have never regretted having my reversal, and I would definitely recommend it if it is medically possible.

Kind regards
JS

Some readers may remember the story, 'You only Live twice' written by James Sharman and published in Tidings *(T36). He said that there had been few occasions where having a stoma had been an issue and he was going to postpone the decision about whether or not to have his stoma reversed for 12 months while he considered the best course of action. Now a year later he says that he plans to have a reversal at some time in 2016 but needs to fit it in around football and work commitments.*

Dear Editor

You may have had this suggestion already, but as a fairly new ostomate I was advised by my nurse to use baby oil in the pouch to help with pancaking. Just squirting sufficient into the pouch has helped enormously. Not only has it sorted out the pancaking, but it has also made the whole process cleaner and it makes the pouch last much longer. I would just add that I use a drainable pouch and the opening at the bottom should be closed first so that the oil does not just flow out.

David from Essex

Dear Editor

Thank you for putting adverts in *Tidings*. I saw the one from Suportx and I emailed them to see if I could have a support garment. I was given a time and day and the lady came to my home and saw I had a hernia around my prolapsed colostomy and my urostomy. She measured me up and applied for a prescription from my doctor and two weeks later I was sent the hernia belt to try. I had to put a sticker where my urostomy stoma was and I sent a pouch so the flange could be measured.

Now I have my hernia belt and it is so comfortable. As the day wore on my prolapsed stoma used to get so big it hurt and I went to bed to make it relax and go small. I no longer have to do this as the belt pushes it in for me.

Kind regards
Margaret Florey

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

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

To contribute to the Readers' Writes page:

e-mail:
editor@colostomyassociation.org.uk

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

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

Editing may be required for reasons of clarity or space.

We want to hear from 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? Please send in an email or letter for our Readers' Writes section.

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 emails are considered by the Editorial Team who decide which will be published in *Tidings* magazine.

If you'd like to send in something for consideration by the Editorial Team for inclusion in Readers' Writes in a future edition of *Tidings,* then please send an email 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 contact details so we can contact you. Additionally, please mention whether the **Colostomy Association** has permission to publish your letter in *Tidings* magazine or not. A consent form will be sent for you to complete before any publication.

Were you involved in the Colostomy Welfare Group in the 1960s?

Do you have any interesting stories or anecdotes from that era?

We'd love to hear from you so that we can put together a special feature in a future edition of *Tidings!*

Helpful Ostomy Support Groups & Organisations

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

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

- IOA International Ostomy Association
  www.ostomyinternational.org

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

- Stomadata
  www.stomadata.com

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

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

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

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

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

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

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

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

Stoma Care Patient Open Day event dates

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

Listings are updated throughout year.

If you are not online

contact CA on:

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

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

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

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Ref. No. SS104

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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:
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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)

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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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Coventry Stoma Support

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.

Martin Robbins & members of the Coventry Stoma Support Group with surgeon, Mr Kashi, who gave a presentation on parastomal hernias at their recent Open Day

I believe that ongoing support is most important in helping ostomates to accept their condition and get their lives back to normal.

My story goes back five years, to a diagnosis of bowel cancer and subsequent surgery, and ultimately a permanent colostomy. After the surgery and other hospital admissions for complications I looked around for support in my local community and, although the local hospital and stoma nurses were excellent whilst in hospital, the ongoing support was very fragmented. I did have contact with the local district nurse and also a Macmillan nurse, but contact with other ostomates was limited to one person in my area. However, his colostomy was reversed so his ongoing situation was quite different to mine.

Sometime during the first few months I found the **Colostomy Association,** after being given a copy of *Tidings* magazine. I can't remember who gave it to me, but it completely changed my outlook over the next few months. As issues arose I now had some contact for help in my rehabilitation. It was whilst talking to someone at the **Colostomy Association** that support groups were mentioned. Again I looked around my area, but there seemed to be nothing or nowhere that ostomates could go and talk with each other about how having a stoma was affecting them.

It was at this point, about six months after my surgery, when I was getting back to some sort of normality that I considered setting up a support group in my local area. It was quite a commitment. I spoke at length with Jackie Dudley at the **Colostomy Association** who gave me lots of information, promised help with producing a leaflet and above all gave me the encouragement to undertake this project.

After making the decision to go ahead, I then decided that meetings would be held monthly. This was quite a difficult decision, but I felt that it was necessary for ostomates to keep in touch on a regular basis. So the first Wednesday of each month was decided upon. Next I had to decide on times, and as I was still working it would have to be in the evenings. I therefore set a time of 7:00pm to 9:00pm. So now to sort out the venue; I had looked round my area and, as I had a link with the local church, I approached the vicar. After discussing my proposal, he kindly offered me a room within the church hall at no cost, and the use of the kitchen so that light refreshments could be prepared for the evening.

To promote the group, a leaflet was designed and produced with the help of Jackie at the **Colostomy Association,** and then I produced copies on my computer. I distributed copies to the hospital, local health centre and local chemists.

So finally on the first Wednesday in November 2011 I started the **Coventry Stoma Support Group.** I deliberately used the word Stoma having learned, both for

CONTINUED ON PAGE 63, COLUMN 1

Marketplace

advertise your events • messages • services here

Stoma care nurses, if you would like to promote your Stoma Care Department, its services and events for FREE, then just get in touch; Contact – **editor@colostomyassociation.org.uk**

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Salts Healthcare Open Day
Kingsmill Hotel, Culcaback Road,
Inverness IV2 3LP
Apr 13th 2016 – 11:00am – 2:00pm
Email: trevor.donald@salts.co.uk

Walsall Manor Colorectal Open Day
Coffee Morning for Patients
Manor Learning & Conference Centre
(Route 301)
Apr 14th 2016 – 10:00am – 12:00noon
Tel: Stoma Care 01922 721 172

Stoma Care Open Day
Richmond Hall, Princess Street,
Rochdale OL12 0JR
Apr 14th 2016 – 10:00am – 3:00pm
Tel Abigail Kershaw 01706 764 267

Beating Bowel Cancer Patient Day 2016
The Royal College of Surgeons of England
35–43 Lincoln's Inn Field,
London WC2A 3PE
Apr 16th 2016 – 9:00am – 5:00pm
www.beatingbowelcancer.org/patient-day-london-2016
Email: info@beatingbowelcancer.org

Respond Healthcare Roadshow
The Doubletree by Hilton,
Kingsway West, Dundee DD2 5JT
Apr 16th 2016 – 10:00am – 3:00pm
Tel: 0800 220 300

Salts Medilink Event
(Mariners Suite) Holiday Inn Plymouth,
Armada Way, Plymouth PL1 2HJ
Apr 16th 2016 – 10:00am – 12:30pm
Tel: 0800 626 388

Coloplast Event
Expanse Hotel, North Marine Drive,
Bridlington YO15 2LS
Apr 18th 2016 – 1:30pm – 3:30pm
Tel: Karen Sutcliffe gbksu@coloplast.com

Coloplast Event
Aylsetone Leisure Centre
2 Knighton Lane, Leicester LE2 6LU
Apr 20th 2016 – 11:00am – 2:00pm
Tel: Stoma Care Team 01233 216 505

Cambridge University Hospital
The Hexagon – The Frank Lee centre,
Addenbrookes Hospital
Hills Road, Cambridge
Apr 23rd 2016 – 10:30am – 2:30pm
Tel: Stoma Care Team 01233 216 505

Stoma Care Open Day
Tingewick Hall, John Radcliffe Hospital,
Oxford
Apr 23rd 2016 – 10:30am – 1:30pm
Tel: Stoma Care Team 01865 221 839

Wessex Stoma Support Group
10th Anniversary Open Day,
Wilton Community Centre, Wilton,
Salisbury SP2 0DG
Apr 23rd 2016 – 10:00am – 4:00pm
Tel: 01722 741 233

Coloplast Event
Future Inn, Hemmingway Road,
Cardiff, CF10 4AU
Apr 23rd 2016 – 2:00pm – 4:00pm
Tel: 07770 494 715

CliniMed Event
Hilton Hotel , Edinburgh Airport, Lancaster
Suite, EH28 8LL
Apr 23rd 2016 – from 2:00pm
Tel: 01628 850 100

CliniMed Event Kaim Park Hotel
Glenavon Suite, 17 Edinburgh Road,
Edinburgh EH48 1EP
Apr 26th 2016 – from 10:30am
Tel: 01628 850 100

Respond Open Day
Double Tree Hilton, Wingsway West,
Dundee DD2 5JT
May 7th 2016 – TBC
Email:
daniel.parkin@pelicanhealthcare.co.uk

Annual Open Day Medway Trust
King Charles Hotel, Gillingham,
Kent, ME7 5QT
May 17th 2016 – 10:00am – 2:00pm
Tel: Fiona Anscomb
01634 830 000 ext 3636

Friarage Hospital
Mowbray Suite, Golden Lion Hotel,
Northallerton, DL7 8PP
May 24th 2016 – 11:00am – 2:00pm
Tel: Stoma Care Team 01609 764 620

Oops Support Group (Middlesborough
and Redcar and Cleveland Area)
Gisborough Hall, Guisborough
(The Drawing Room)
Jun 7th 2016 – 1:00pm – 3:00pm
Tel: Julie Morrisroe 01287 284 113

Oops Support Group (Middlesborough
and Redcar and Cleveland Area)
Dorman Museum, Middlesborough
(Education Room)
Oct 4th 2016 – 1:00pm – 3:00pm
Tel: Julie Morrisroe 01287 284 113

POUCH COVERS

Designed by Ursula Naish

Ursula Naish designs and produces pouch covers and waterproof mattress and wheelchair covers.

As Secretary of the UA Kent Branch she offers this service to raise funds for her local group.

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

CONTINUED FROM PAGE 61, COLUMN 3

myself and from the **Colostomy Association,** that there are very many issues that affect people with ileostomies and urostomies as well as colostomies because we all have a stoma. I am glad to say that this decision has in the long term been proved to be the right one.

The very first meeting was attended by just two ostomates and, as it turned out, one of them was someone who became a good friend, and was present at almost every meeting for many years. I later found out that he was a volunteer for the **Colostomy Association.** He also introduced me to irrigation which I took up later. Unfortunately he sadly passed away last year, but I will always remember him for his encouragement and help in promoting the group and in raising awareness of ostomies and the work that was being done by the **Colostomy Association.**

When I made the decision to start a support group I also decided that the objective was to provide a social, informal atmosphere where colostomates, ileostomates and urostomates their partners and friends could meet to share stories experiences and emotions. Although it is not a medical group, we do from time to time arrange visits from stoma care nurses and invite guests from ostomy supply companies.

Over the first few months the numbers varied but in general were a little disappointing, as on average only five or six people were turning up on meeting nights. This gradually started to improve, and in the second year we entered a team made up of ostomates, friends and relatives into the local Walkathon. We all turned up in specially commissioned tee shirts promoting the group, and not only did it give us all a real lift, but we were able to make quite a good donation to the **Colostomy Association.** We even had comments from members of the public, mostly asking what we were representing. It did at least get our group and the **Colostomy Association** noticed.

As time went by there was a gradual increase in the numbers attending the monthly meetings and it became clear on more than one occasion, that individuals were getting a real benefit from meeting other ostomates. In fact a lady who was very reluctant to venture out of her home, is now a regular member, and has told us that the meetings have really helped with having a better understanding of her medical condition, and how to cope with it on a daily basis. That is why I believe it is so important to have regular group meetings.

Having a stoma can be the result of many conditions, not only bowel cancer. It may be necessary to treat ulcerative colitis, Crohn's disease, diverticulitis and other bowel problems. I did find it strange when talking to some members that, due to an emergency procedure, they were in fact not actually aware of what type of stoma they had! Again another good reason for good communication within a support group.

As the group has been running now for about four years, it has built up considerably, so that between 12 and 18 members turn up on most meeting nights. Sometimes it can become a somewhat noisy affair, with different people talking amongst themselves about differing subjects, but this adds to the openness and sociability of the evening. As time has gone on, we have made quite a few new friendships. It seems that with all ostomates together we talk more freely and openly, and this then gives us more confidence and helps to supress some of the worries and anxiety about having a stoma.

During the autumn months of 2015, I discussed with the group the possibility of having an Open Day for ostomates in Coventry during November. We agreed that it would be best to have a focal point or subject, and chose parastomal hernias as this was a topic on most ostomates' minds. I then set about finding a local venue, and contacting various stoma appliance manufacturers and supply companies to offer them some participation on the day.

On the 20 November 2015 the Open Day meeting took place at the Coventry Rugby Club and seven stoma appliance companies attended. Two stoma care nurses also came along, one from Nuneaton and one from Coventry. The latter was instrumental in arranging for a senior colorectal surgeon from Coventry University Hospital, to present an excellent, interesting and at times amusing presentation on parastomal hernias; their prevention, and repair. This was undoubtedly the highlight of the Open Day, and our thanks go to Mr Kashi, who I think impressed all of us with his commitment to furthering the awareness of and importance of the management of parastomal hernias. I am pleased to say that the day was a success, and the feedback from both the stoma companies and ostomates was very positive.

The Coventry Stoma Support group, with the help of the **Colostomy Association,** will continue to support all ostomates, not only in our local area but also nationally, and hopefully we can help them with reassurance, understanding and encouragement to continue living and enjoying life to the full.

Martin Robbins

Thank you to Martin and members of the Coventry support group for donating **£255.00,** the amount raised at their Open Day, to the **Colostomy Association.**

The success of the Open Day also generated local publicity and the group has now grown, so the current meeting place is too small and it has been necessary to hire a larger room in premises nearby.

The next meeting will be on Wednesday 4 May. For more details contact **Martin** on **07947 385 643.**

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

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

Stoma support groups
in your county

England

B

Bedfordshire
Saturday Social Club
Karen Richards: 0123 479 2278

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

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

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

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

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

C

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

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

Darlington Support Group
Sister Jacqui Atkinson: 01325 743005

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

D

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

E

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

G

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

Vale Stoma Support Group
jfn.dursley@gmail.com or text 0794 182 7393

H

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

I

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

K

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

L

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

March Group
Sharon Palmer: 0741 482 8867 or sharonpalmer44sp@gmail.com

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

M

Merseyside

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

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

Middlesex

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

N

Norfolk

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

Stars
Anne Browne: 0160 366 1751

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull: 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 Stoma Support
Jenny or Kate: 0115 962 7736/ Mrs B Heath: 0115 966 3073

O

Oxfordshire

Oxfordshire Ostomy Fellowship
Pat Longworth: 0123 552 4163

Shropshire

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

Somerset

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

Staffordshire

Outlook
Moira Hammond 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

T

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

W

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

Y

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

Scotland

A

Ayrshire

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

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

F

Fife

Fife Ostomy Support Group
Ishbel Barr: 0159 277 2200

L

Lanarkshire

G66 Support Group
Les Ireland 0141 776 3866

Northern Ireland

C

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

L

Londonderry

Causeway Support Group
Mary Kane: 0287 034 6264

Channel Islands

G

Guernsey

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

Republic of Ireland

C

Co. Mayo

Mayo Stoma Support
Marion Martyn: 094 902 1733

D

Dublin

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

Rest Of The World

F

France

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

K

Kosovo

Kosovo Ostomy
Arta Uka: kosovoostomy@gmail.com

S

Spain

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

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Peter's story

After 8 months, Peter and Val are beginning to live their old life again, after Peter's stoma operation.

Peter Hart used to enjoy playing golf with his friends and holidays with his wife, Val, which they thought would all have to be given up when he had a colostomy operation in June 2015.

When he was released from Kings Mill Hospital in Nottinghamshire, Peter was placed onto a home delivery service with respond. The service has supported Peter and his wife, Val, to get back to doing the things they did before the operation, that they most enjoyed.

"Right from the very start, the support from customer service has been second to none. It is quite a change to your life and respond has offered all the support that we needed. The service has been very, very good", said Val.

"Respond has offered all the support that we needed"

"Tracey is our main point of contact, she's been amazing", said Val. Since Peter felt weak after leaving hospital, and had lost a significant amount of weight, he had a few challenges that needed looking at. First off, he was unsure whether he could play golf again.

Talking to the respond Customer Support Team helped Peter get back on the course.

"We had no idea there were so many different products. Tracey has been great with ideas of things to help Peter get his old life back" said Val. "She'd suggest things he needed, and with the help of the support belt he is playing golf again."

"The support we get has made a big difference."

"The Ostomart adhesive remover is amazing and when we were running a bit low, respond arranged to drop some off before our next delivery was due. That was in the early days when we hadn't quite got adjusted."

Now Peter or Val speak to respond just ahead of their delivery date to check their repeat order and talk about any other requirements.

"It just seems to work like clockwork"

Peter says "It just seems to work like clockwork. They just do respond to us very well. It's not just an ordering service. They listen and respond."

Now, with reassurance from respond, Peter and Val can look forward to their next holiday in a log cabin with hot tub and swimming pool.

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.

If you wish to chat about the change, simply give your usual customer service office a call, and they can help reassure you that whilst we've made some changes, we are still the home delivery service that you have always relied on.

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Come and say hello

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an eakin company