Autmn 2014 | Issue 35

colostomy association

Tidings

Dedicated to Colostomates their Families and their Carers

Cover story

- Dreams do come true

Inside

- Do you Measure Up?
- I have a Colostomy because…
- The Rectal Stump
- And all our regular features


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* ConvaTec data on file. Esteem(R) PLUS product evaluation survey conducted in 100 patients (2012)
†Product comparisons are related to other ConvaTec products.

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For a media pack and advertising rates.

Contact –
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dear READERS

In recent months photographs have been posted on the internet and appeared in the press which have gone a long way towards removing the misconceptions and taboos which have always surrounded colostomies and other types of stoma.

Hopefully, the general public will no longer associate colostomies with old age, and they are now aware that cancer is not the only reason that people have to wear a colostomy bag. In this issue we aim to expand on this theme, beginning with an article on the many different reasons that a colostomy may be necessary.

The bride who appears on the cover did have her colostomy because of cancer - indeed she was told it was inoperable. Anne Gray's amazing story tells how the doctors were wrong and dreams do come true. The other four real life stories are from people whose stomas were the result of an accident, a perforated bowel, and problems with bowel function, one present from birth, the other which developed in later life.

We are very grateful for the generosity of professionals who give their time to write articles for *Tidings*. This time we have three: two about stoma related issues; the other of general interest.

In an article entitled *The Rectal Stump*, Clinical Nurse Specialist, Yvette Perston, explains why some people experience a discharge from their rectum even though they have a colostomy. When reading about children with bowel problems in *Tidings*, you may have come across the term **ACE** and wondered what it meant… Rachel Wade, Children's Gastroenterology Specialist Nurse, explains. Thanks, as always, to Julie Rust for answering all your letters and e-mails.

As next month is Free Wills Month, Solicitor, Rachel Fuller, has very kindly written an article about the importance of making a Will – an amazing 60% of the population don't have one. We also include a reference to solicitors who are offering a free Will writing service allowing you to make a donation to a charity of your choice; **Colostomy Association** comes to mind as a suggestion!

Letters and e-mails about the delay which can occur between ordering ostomy supplies and receiving them from the delivery company are still coming into the office. We have, therefore, included an article which outlines the different ways of ordering prescription supplies. Other practical issues include Sarah Squire's column on irrigation. This time she takes us *Back to Basics* to encourage those of us who are thinking about this method of managing their stoma to go ahead and try it.

Jackie Dudley's article encourages us to go along to one of the many support groups around the country – we are continually being asked to add more groups to our list on pages 64-67; the new layout should make it easy to find a group near you. The Facebook page this time is about their latest 'mini meet'. There's also news of the Junior Ostomy Support Helpline (JOSH) where trained volunteers will offer practical peer support to parents of children with bowel and bladder diversion/dysfunction.

So it seems that not only is there an increasing awareness of stomas among the general public, but there is also more support at local meetings, over the phone and on line for people, like us, who just happen to have a stoma.

Thank you for all your letters and e-mails. We look forward to hearing from you.

The Editorial Team

Email:
editor@colostomyassociation.org.uk


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

How to become a member of the Colostomy Association

Simply contact us by post:

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

By telephone:
General Enquires: 0118 939 1537

Stoma care queries only:
Freephone Helpline: 0800 328 4257

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

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inside this issue

all your regulars & special features

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Focus on

Support

colostomy association

The Colostomy Association is a charitable company limited by guarantee (Registered Charity No: 1113471).

A **New** Lease of **Life**

> **"...born with Hirschsprung's disease, but he was 36 before it was diagnosed. "**

Jamie Smith tells his story... how he was born with Hirschsprung's disease, but he was 36 before it was diagnosed. Having a colostomy has meant that he is now pain-free and his life is a lot better... so much better that he has now taken up cycling, which has, not only made him fitter, but also raised money for the Colostomy Association.

I have had bowel problems since birth! I didn't know what was wrong with me until I was referred to a specialist when I was 36 years old. After being unwell throughout Christmas of 2008, I finally had enough of being in permanent pain and the effect this was having on my life.

I went to see my GP and he sent me to Queen Elizabeth The Queen Mother Hospital in Margate. The consultant examined me and found a mass in the right hand side of my abdomen. I thought the worst and had to wait two weeks for a scan. The scan showed a build-up of poo in my bowel. After lots of tests and a bit of a wait, I was finally diagnosed with Hirschsprung's disease.

Hirschsprung's is a disease that affects the last segment of the large bowel (sigmoid colon) and the rectum, and it basically means there are no nerves there that send a message to your brain telling you that you need the toilet. It is usually spotted at birth, and only rarely is it not picked up until adulthood. My bowel at this point was massively distended – the size of my thigh when it should be the size of the wrist. It was pushing against the vein that pumps blood up to the heart. My resting heart rate was 120. The only choice was surgery.

On the 31st March 2011 I had surgery at University College Hospital, London. It was the day I was given my stoma. I knew this was going to be the outcome and had plenty of time to get used to the idea. After surgery I immediately knew I felt better. My body was finally working properly. I wasn't bloated and full of poo! As I recovered from surgery I quickly got used to life with a stoma and the adjustments I had to make, and found living a pain-free life was a lot better.

Three years on I am healthier and fitter than I have been for years. I took up cycling to lose the post-surgery weight I had gained and started to enjoy it more and more. Then I decided to do something useful by setting up a JustGiving Page and taking on a 65 mile bike ride to raise money for the Colostomy Association. Not many people knew about my colostomy so through fundraising and advertising my Just GivingPage on Facebook, people that previously hadn't known would find out. It took me a few days to pluck up the courage to go ahead. I finally did and I had nothing to worry about. The support I received from friends was incredible.

A 65 mile bike ride was definitely not something I would have considered a few years ago but I really enjoyed the challenge, both the training and the ride. The ride itself was a tough, hilly route which challenged a lot of the riders. I completed the 65 miles in just over 4hrs 30mins. A solid achievement! And, I raised £320. I have booked myself onto more rides this year with the goal of the 100 mile Great Kent Ride in July.

Because my stoma has retracted and the opening is stenosed (narrowed) I am on the waiting list to have surgery to refashion my stoma later this year. I will be keen to get back on the bike so I can imagine the recovery time will be a frustrating one!

Jamie Smith

What is Hirschsprung's disease?

This condition is named after Harold Hirschsprung who first described it in 1886. It occurs where ganglions (nerve cells) are absent in part of the bowel.

The bowel is a long tube, coiled around inside the abdomen, and food and digested matter are moved along it by a series of wave-like contractions called *peristalsis.* This involves the alternate contraction and relaxation of muscles in the bowel wall. The absence of ganglions means that although the bowel can contract to push the motion it can't relax to allow it to move forward. This leads to pain, constipation and blockage. The rectum and lower part of the large bowel (sigmoid colon) are the areas most often affected but it can in some cases extend to the whole colon and in rare instances the small intestine (ileum) as well.

It is more common in boys than girls and is often diagnosed in the newborn when meconium (the sticky, black substance that lines a developing baby's bowel during pregnancy) is not passed out through the anus during the first 24 to 48 hours. Other symptoms include bile vomiting, a distended abdomen and poor feeding. However, some cases go undiagnosed until early childhood, but there is usually a history of bowel problems and constipation.

Hirschsprung's disease is diagnosed by using a number of techniques. The most vital diagnostic tool is the rectal biopsy whereby a tissue sample is taken from the rectum and studied under a microscope to see if ganglion cells are present.

Treatment involves surgery where the affected part of the bowel is removed. This may be performed in stages with a temporary colostomy (or ileostomy) formed to allow time for the lower bowel to recover. In some cases the stoma may be permanent.

For more information visit:

Hirschsprung's & Motility Disorders Support Network (HMDSN)

www.hirschsprungs.info

www.nhs.uk/conditions/hirschsprungs-disease

colostomy association

CA

awareness day

CA Awareness Day – update

On 4 October 2014 we launched our first ever **CA Awareness Day** and one of our wonderful supporters, Steve Clark (pictured here), offered to wear a purple wig while taxi-ing.

What an excellent way to raise our profile - thanks so much Steve. This must have caused a quite a chuckle for some of your fares! An update on all the activities will be provided in the Winter edition of *Tidings* so if you did get involved in this special day do let us know as we'd like to create a montage of everyone's efforts! It is hoped that this event will become a big success, developing year on year. Our thanks go to everyone who took part.

A Week in the Life of "El Presidente"

From our President
Mr Ian Daniels, Consultant Colorectal & General Surgeon

Saturday: Council of War... doh, no, Trustee's Meeting. Sat at the table, surrounded by *Generals*, *Colonels* and other military types... there was Monty (*Chief of Staff*), Wells (*Ideology*), Levy (*Minister of Defence*), Dudley (*Intelligence*), Squire (*Home Front*), and Andrews (*Strategy and Propoganda*), missing in action were Gunning, Hulme and Hatton (presumably undercover on a secret mission although it does have the ring of a furniture store! 'Come to Gunning, Hulme & Hatton for all your furnishing needs.' Perhaps they were choosing scatter cushions!!) Sat through listening to plans for world domination and discussing strategy over sandwiches! **"Keep Calm and Carry on"** I said... catchy, I might market that one on mugs.

Sunday: Having returned from meeting, spent the day cutting the grass thinking about driving tanks, big guns, overseas battles and whether the main thrust of the attack will come from east or west... grass now has funny pattern! Got in trouble for that from First Lady! She was more concerned that I wasn't doing battle with the mole! Told her it had become an underground resistance operation!

Monday: Back to Day Job... defending the NHS against the mass of media critiscm (the difficult bit), and trying to keep a few people alive a bit longer... (the easy bit).

Tuesday: Received message from Hatton, deep under cover, but well and making progress... Turing's invention now has an Apple on it... he would be proud. No sign of scatter cushions though, but concerned Hulme may be a PoW as he kept talking about prisons! Remember Ernie Name, rank and number, give nothing away!

Wednesday: PMQ's... no Outpatients!! Decided communication is the key to good health care... need to flag that up in next speech, talk to patients, it's surprising how well they respond. Informed juniors it led to fewer complaints, they went back to order tests by computer!

Thursday: Operating Day – Dawn Attack, lots of colleagues for a major operation, colorectal in first, supported by urology, vascular on stand-by, orthopaedics with the heavy weapons to break bones, 11-hour battle, colorectal maintained fight, urology went for a wee, at the end of the day, victory was ours, Intensive Care offered support for peace-keeping duties over next 4 days.

Friday: Colonoscopy list, what fun can be had with lines like *"lets see where the sun don't shine"* only to realize it had... no tan lines!! Doh, forgot that people in Devon have bigger gardens and not nosey neighbours! PM better, Outpatients again, realized I must be getting better, a room of survivors, or is that lucky?

End week with realization that World Domination proving to be hard work, good job we have fantastic generals though!

Open Day 2015 & Fashion Show

Colostomy Association celebrates 10 years

Date:	**Saturday**	**11th July 2015**	**Sunday**	**12th July 2015**
Time:		**9:30am - 4:00pm**		**10:00am - 1:00pm**

Plans are progressing very well indeed for our celebratory 10th anniversary next year.

We do hope you'll join us on **11-12 July 2015** for the special celebrations. We're optimistic that all 22 exhibition stands will be booked at the **Open Day** taking place on the Saturday as manufacturers and suppliers are always keen to be represented.

The Gala Dinner on the Saturday evening will be a very special occasion, so do put the dates in your diary.

There will be a celebratory cake, awards ceremony and some cabaret style entertainment, while the fashion show on the Sunday morning will also offer a bag swap activity so please dig out any handbags you no longer use and keep them on one side for us.

We're hoping to raise extra funds through this unusual activity – not to mention publicity in the local papers.

A sponsorship opportunities list has been circulated to the exhibitors in the hope they will cover some of the expenditure and so far **£7,500 has been pledged** towards the cost of the fashion show and other items so that's a great start!

We'd be delighted if you could join us so why not make a weekend of it?

A booking form will be available in the winter edition of *Tidings*, which comes out in January 2015 so book early to avoid disappointment. Hope to see you there!

The Year of the Stoma

due to emergency surgery for a perforated bowel

On the morning of Monday 17th July 2007 I was particularly happy. Summer term had just ended so I had six weeks of holiday from my teaching assistant job ahead, my husband was due back from a three week research visit to Australia on the Friday and my first grandchild was due in August. Life seemed very good – I was listening to Women's Hour on the radio, and my 16 year old son was asleep as usual upstairs.

I felt a need to rush to the downstairs toilet and whilst sitting there fell forward with agonising and unexpected pain. I recall trying to shout my son's name but being able to do so only weakly. After what seemed like hours, he arrived sleepily at the toilet door and asked what was wrong. I replied: "This is the worst pain since childbirth", (in my family the gold standard for pain after two 3 day labours) and he said: "Better ring an ambulance then." I recall a paramedic trying to open the toilet door to get to me, and then…

I awoke eight days later in Intensive Care.

So this part of my story is what everyone told me later. I was admitted to A&E and there were several hours of uncertainty about what was causing the pain. Fortunately an experienced consultant noticed how ill I was and took over the case, sending me for an X-ray which revealed air in the abdomen which meant a perforated organ, probably the bowel.

He arranged for emergency surgery as the contents of the bowel would be leaking into the body poisoning my system. My son called his best friend's mother who came to the hospital and spoke with the consultant. He said that my husband should be called as there was an 80% chance that I would die in the next few hours. She called my husband in Sydney, and the doctor explained to him that I was to go into emergency surgery for a perforated bowel, would probably not survive, and he needed to return at once.

My husband immediately left for the airport where he got the next available flight to the UK with 32 hours of travel ahead not knowing what he would find on arrival. It doesn't take much imagination to realise what a nightmare journey that must have been. My elder son was also called back from Sri Lanka where he was volunteering in a children's home. They called my brother as an adult could be needed to make life and death decisions.

The operation lasted several hours in the middle of night – nearly a foot of bowel was removed and a stoma created to allow the bowel to heal. A lot of bowel content had dispersed around the body causing severe sepsis. After the surgery I was taken to ICU, ventilated and sedated and not expected to survive.

My husband arrived back very early Wednesday morning and the driver rushed him from Heathrow to Leicester to see me in ICU – the usual frightening scenario with lots of tubes, machines breathing for me, feeding me through tubes and monitoring all my vital signs.

Over the next few days his life had the nightmarish quality you would expect – hours at my bedside, going home to deal with phone calls from family and friends, feeding the children, and trying to keep some sort of normality in the home, whilst being told that the staff were concerned that I had not come round, and each day like that was increasingly worrying.

I meanwhile was in a horror movie in my head where I was being held prisoner in the desert in the Middle East and then taken to an institution where I was to have my organs harvested whilst I was still alive. (I later learned that such hallucinations are normal and a result of both the drugs given and the general sedation experience.)

When I awoke I saw my husband hovering at the end of the bed like a hologram and assumed it was some new Skype phone development where he could send me his picture whilst telephoning from Australia. He was unable to convince me that he was in the UK or that I had had emergency surgery and a colostomy. I believed the staff were lying to him (paranoia is a key feature of a stay in ICU).

After eight days, I was transferred to a general ward where I spent five weeks recovering, and was discharged with a colostomy and an 11 inch long open wound – my abdomen had burst open after the surgery because of the systemic infection I had. Naïvely my husband and I thought that the wound would close in a few months and I would quickly regain my strength and become one of those people where others would say: "Isn't she marvellous? She's had a colostomy but you'd never know". It was a longer journey.

Some people give their stoma a name, I read in this magazine. No, that's just weird, I thought. Who knew what gender a stoma had? And I wasn't intending a long-term relationship with it (it definitely was an 'it', like a machine, garbage in and garbage out, didn't they say?) They said it could be reversed eventually or, as my consultant baldly put it: "no surgeon would want to go inside you for the next twelve months" because it takes that long for sepsis to leave your system. It was going to be **The Year of the Stoma**.

On the ward other patients said I should treat it with love and kindness because it had saved my life. Many of them had cancer where it wasn't clear whether their surgery was successful, but mine was simpler, my bowel had blown itself apart, and the stoma was protecting it whilst it healed.

It was a very healthy looking pink colour and still until the muscle ripples from further up the system reached it, and then it moved autonomously. I was surprised I had no control over it. I was taught by the stoma nurses how to keep it clean, with a system of wipes and creams being careful to clean every crevice. I found myself smiling at it whilst I cleaned it, taking it into the shower for a good wash and carefully drying it with a soft towel. I got upset when it had a rash, or soreness, and tried different creams, wipes and bags to keep it as comfortable as possible. I bought it pretty soft cotton fabric covers from eBay, so that the bag didn't rub my skin and people weren't horrified if they caught a glimpse of my stomach. I introduced it to disabled toilets, some public ones which I entered with a special RADAR key for the disabled, some in shops like Marks and Spencers, feeling people looking at me because my 'disability' wasn't obvious.

When it was working when I hadn't got a bag on, I watched it, admiring the fantastic way it moved, musing that all this had been going on inside me for 50 years and I'd never known, but now I could actually watch something that most people will never see. It was like the *Playdough* machine my children had, where you pushed the clay into a tower and then through various shapes to produce a long sausage. Generally it had a consistent shape and colour, but some food could really change it. Who knew that mushrooms pass through with their shape almost untouched? And sweetcorn, you could have picked it out intact.

Surprisingly it developed its own rhythm again, just as it had when a complete system. So it went just after breakfast, and then again later in the day if I had something that went through my system too quickly. I could sometimes feel the sensation of the ripples of pulsating muscle as it began to work. My left hand often rested over the stoma, protecting it maternally, when I watched TV.

By the next summer, the stoma and I were mates, we understood each other, what upset it, what didn't, what made it do noisy stoma farts, which bags and creams and wipes were the most comfortable, which clothes could be worn and which couldn't. You wouldn't have known I had a stoma if I hadn't told you, if you saw me queuing in Sainsbury's or at the pictures.

I did adapt well to having a colostomy, being in a wheelchair for a few months, and to every aspect of my life being medicalised. I found the support of organisations like the **Colostomy Association** and ICUsteps invaluable although I was increasingly irritated by the stories of how so-and-so had climbed Everest with a stoma, or travelled round China or the Amazon basin. I'd never wanted to do those things before I was ill and I certainly didn't now! I found the incessant cultural clamour to be a 'brave' patient, to bear quietly and stoically my misfortunes, and to keep quiet about them as the months went by, and family and friends were ready to move on and I wasn't, particularly difficult.

The wound was still open when I returned to the hospital a year later to have the colostomy reversed. The night before the operation, I stroked the place where it was, feeling sad, and grateful, and pleased to have had this unusual experience. I would have to admit I shed a tear as I said goodbye.

Barbara Buck

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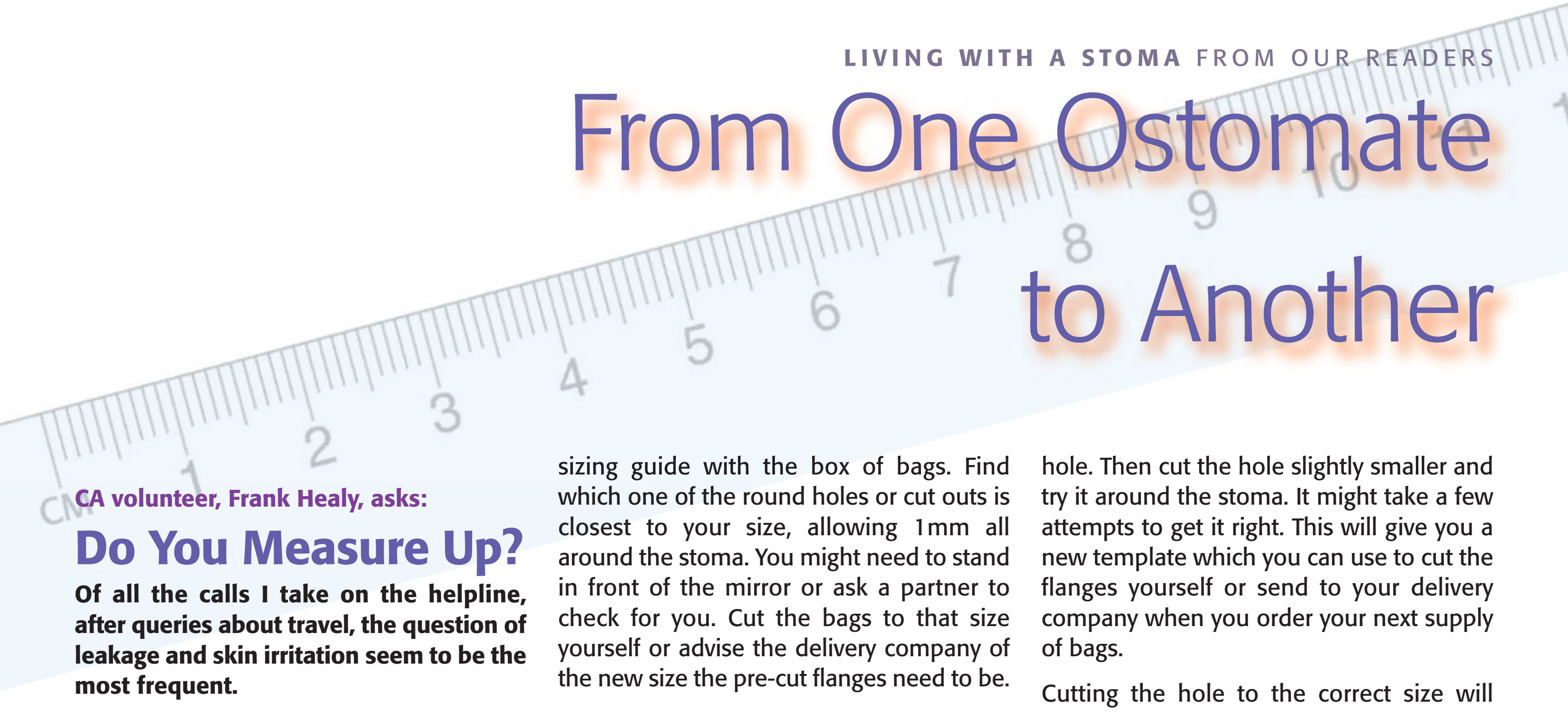

From One Ostomate to Another

CA volunteer, Frank Healy, asks:

Do You Measure Up?

Of all the calls I take on the helpline, after queries about travel, the question of leakage and skin irritation seem to be the most frequent.

All the normal advice about the use of adhesive removers and barrier creams, more often than not, is answered with: “I’ve tried all those!”

I then ask the question: “When did you last measure your stoma to check if the hole in the flange of your bag is the right size?” The reply is often: “Er…I don’t know.” Or “How do you do that?”

Measuring your stoma regularly is very important to make sure that the cut hole is not too small so that the flange rubs on the stoma and not too large so that the contents of the bag come into contact with the skin around the stoma causing irritation or leakage.

Changes to the size of new stomas are normal during the post-operative period. Initially after surgery the stoma is swollen due to the trauma. This swelling will gradually reduce over a period of time, and usually after six weeks it has settled down. Unfortunately no one can tell you how large the stoma will be after the operation or how small it will become. The stoma nurse will check this over during the first couple of weeks but after that it is up to you to keep a close watch on it.

Changes to the size and shape of established stomas can also occur over time. Most commonly the change is due to weight gain or sometimes it can be due to weight loss or a parastomal hernia.

It is very simple to check that you have the right sizing. Most manufacturers send a sizing guide with the box of bags. Find which one of the round holes or cut outs is closest to your size, allowing 1mm all around the stoma. You might need to stand in front of the mirror or ask a partner to check for you. Cut the bags to that size yourself or advise the delivery company of the new size the pre-cut flanges need to be.

An alternative way, particularly if your stoma is not round, is to use the plastic backing sheet which protects the adhesive on your current bag. The hole in it will be the same size as the hole in the flange. Put it in position around your stoma as shown in diagram. If the hole is too small mark where the backing sheet is touching the side of the stoma, then cut this area slightly bigger and try it again. If the hole is too large then you will need to place the backing sheet on a piece of paper and trace the outline of the hole. Then cut the hole slightly smaller and try it around the stoma. It might take a few attempts to get it right. This will give you a new template which you can use to cut the flanges yourself or send to your delivery company when you order your next supply of bags.

Cutting the hole to the correct size will ensure that any sore or irritated skin that may have been exposed previously is covered. The baseplates are made of hydrocolloid which has healing properties and is kind to the skin. The skin will often heal within 24-48 hours.

If you are unsure if the hole in your flange is the correct size, or you would like help in cutting a template, consult your stoma care nurse.

Frank Healy

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

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

Correct size template

Incorrect size template

Two colostomates speak out:

in Support of Drainable Bags

I was so pleased to read Sheila’s hints & tips in the latest *Tidings* magazine.

I thought I was in a minority of one in using drainable bags for my colostomy. Even my stoma nurses seem to think I’m something of an oddity in preferring them to closed bags.

In my opinion it makes sense to use drainable bags. They’re easy to empty, avoid the necessity of disposing of full bags, you use fewer bags each day (kinder on the skin) and it’s much easier to get rid of wind.

Ione Lee

I use a drainable pouch and after I’ve emptied it I wipe it, then pour a small plastic jug of warm water inside, swish it around and empty the water out.

I do this a couple more times until when the water comes out again it is almost clean.

Patricia Fisher


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Obtaining Prescription Supplies

On discharge from hospital you will probably have been supplied with the products and supplementary products that you are currently using. You will be given the name and contact details of the supply company and your stoma care nurse will also give you a list of these products and their relevant order code so that you are able to obtain future prescriptions from your GP. Or they may give this to the GP/surgery directly.

Please bear in mind that in all cases, a prescription needs to be obtained before any supplies can be sent out.

To arrange repeat prescriptions there are a number of options.

1. **The Supply Company handles everything** You can call them when you need to place an order, or very often they will call you on a monthly basis. They will then contact your surgery to get the prescription for your order and with that in hand will send out the order to your home, in unmarked packaging. They will include complementary wipes, disposal bags and they will cut flanges to size. They will also offer advice.
2. **You get the prescription and the Chemist fulfils the order** If you want to use a chemist then you will need to arrange for the prescription from your GP. Repeat prescriptions can usually be handled online and can be sent to the chemist of your choice. Chemists then provide two levels of service. All chemists have to offer Essential Services and they will provide you with complementary wipes, disposal bags, a home delivery service and advice. If they are signed up to Advanced Services they will also cut the flanges for you.
3. **You get the prescription and send it to the Supply Company to fulfill** You get the prescription from the GP and then send it in a Freepost envelope (supplied by the Supply Company) to the Supply Company of your choice and the order complete with complementary wipes, disposal bags and flanges cut to size will be delivered to your home.
4. **You ask the GP to send the prescription to a Supply Company** You contact the GP to ask for the prescription which the surgery then sends to a Supply Company which could be one they use or one that you specify. Again Supply Companies supply Freepost envelopes and the order complete with complementary wipes, disposal bags and flanges cut to size will be delivered to your home.
5. **Your GP practice is a Dispensing Practice** If your GP practice is a Dispensing Practice they will probably prefer to fulfil the order through the dispensing arm of the practice rather than involve a DAC or other chemist. Again the GP will raise the prescription – you may be able to make a request for a repeat prescription online. The GP will then pass the prescription to the Dispensing arm of the practice. If they are signed up to offer Essential Services they will provide you with complementary wipes, disposal bags, a home delivery service and advice. If they are signed up to Advanced Services they will also cut the flanges for you.

It is worth knowing that the license conditions of the Supply Companies – called **Dispensing Appliance Contractors** (DACs) – state that they must supply all products listed in Part IX of the NHS Drug Tariff, which includes a broad range of ostomy and urology products. If they do not have the products in stock, medical product wholesalers exist to supply them with these products at short notice.

Supply Companies (DACs) are often integrated within stoma care product manufacturers/companies – such as Coloplast *{Charter}*, Hollister/Dansac *{Fittleworth}*, CliniMed *{SecuriCare}*, ConvaTec *{AmCare}* and Salts Healthcare *{Medilink}*. However there are several other independent DACs e.g. *Wilkinson Healthcare*. And all DACs will supply whatever brand of product is prescribed, no matter which manufacturer they are integrated with.

If the Supply Company (DAC) or Chemist (also called a Pharmacy Contractor) cannot dispense the item prescribed or cannot provide the required stoma appliance customisation, they must (with the patient's consent) refer the prescription form or repeatable prescription to another Supply Company or Chemist. If the patient does not consent to this, then the Supply Company or Chemist must provide contact details for at least two other contractors who may be able to dispense the required item or service.

Supplementary Products are a very important part of managing one's colostomy and they are an intrinsic part of the order and hence prescription. They can be seen by some GPs as extras and possibly an area where cost savings can be made. Assuming that their inclusion in the order has been approved by the stoma care nurse and the quantity ordered is sensible and appropriate then any patient who is meeting resistance from a GP should refer them to the stoma care nurse for confirmation of the need for the supplementary products to be included in the order.

Emergencies/Urgent Supplies In an emergency one can get supplies from a Supply Company or a Chemist without them being in possession of a prescription as long as your GP has agreed to give them a prescription for the supplies within 72 hours. If you can't get hold of your GP then the Supply Companies will very likely help you out and get you some supplies to tide you over, although without a prescription and unable to get a retrospective prescription they would have to bear the cost.

Prescription Charges

Colostomates living in the UK whose stoma is permanent are entitled to apply for a Medical Exemption (MedEx) certificate, which entitles them to obtain all prescriptions free.

Colostomates with a temporary stoma DO have to pay prescription charges for stoma appliances unless they are eligible not to for a number of reasons including, because they are over sixty, are being treated for cancer or are on benefits because of low income. For the full details, see the NHS prescriptions web page: **http://www.nhs.uk/NHSEngland/Healthcosts/Pages/Prescriptioncosts.aspx**

NOTE: One should allow up to three weeks from placing the order with a Supply Company until it is delivered to one's home.

I Survived

I look down at my stomach and see my scars: one is thin, running vertically past my belly button, the other horizontal, shorter, thick, and intrusive.

I like to call these imperfections on my stomach my ‘battle wounds’. These scars permanently mark my body, and they symbolize my strength to overcome life’s unforeseen hurdles. At 25 years old, I faced a near death experience and an immediate surgical decision resulting in a colostomy. Walking away from a plane crash and the two surgeries that followed taught me the infinite value of taking control of my health as it closely ties to my quality of life. Four and a half years later, I reflect on the experience.

One afternoon in the autumn of October 2009, my parents and I were traveling from our home in Northern Kentucky to my cousin’s wedding in Charleston, South Carolina. My dad was the pilot, and the plan was to turn back if the weather deteriorated. As we flew over Virginia, the fog rolled in and we couldn’t see where we were heading. When the accident happened I experienced a profound pain as the seatbelt punctured my colon, and the “Oh my God” reality that we had crashed; it forced me to accept that death was a possibility. Miraculously that puncturing pain didn’t result in death, the plane didn’t catch fire and with every breath my chances of survival grew higher. Unknowingly, I disconnected my mind from my pain and zeroed in on the fact that we were down, lost in a very thickly wooded, mountainous area.

During those unforgettable hours following the crash I became a person I never knew existed. In the midst of severe abdominal pain, I kept my parents calm and directed both emergency crew and family to the crash site. Alone, I walked hundreds of feet down forestry mountain carrying bags of clothing, using them to mark a path back to my parents. I consciously talked myself out of the discomfort, referencing my experience running a marathon. Hope was at my side, and I knew I wouldn’t survive if I gave in to the pain. It wasn’t until I saw the rescuers that I was able to surrender to my emotions; the tears fell as I begged them to find my parents and get us help.

I often replay my experience of survival and what happened at the hospital, because I wonder if a colostomy and the stomach issues I still experience today could have been avoided. Although I had just survived acute trauma, the attending doctors diagnosed colitis and I was prescribed pain relief and sent off in the care of family members. While my sisters and parents were an hour away at a different hospital, I lay awake that night in a hotel room in shock and pain, but still believing the evaluation of the health professionals. It was another 48 hours before I returned to hospital for another evaluation. At this point my abdomen was so distended that it was plainly evident to the doctors that I needed urgent surgery. I looked into the eyes of my sister, who is a nurse, for answers, but deep down I had a premonition that I would need a colostomy.

After a total evaluation of my abdomen during surgery, it was confirmed that my colon was damaged in two places: torn in two and split lengthwise. A portion of my colon had to be removed, and a colostomy put in to allow the colon to heal. The good news was that it would be reversed in three months. Lying in the hospital bed three days after seeing my life flash before my eyes, the pain medication fogged my awareness of the colostomy.

I received a lot of visitors interested in hearing my survival story, but I always felt uncomfortable, conscious of the stoma, the noises, the smell, the need for maintenance. Nobody could understand what I was going through. I would sit there

CONTINUED ON PAGE 20, COLUMN 1

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CONTINUED FROM PAGE 18

after a visitor left and replay the embarrassment. It was a real emotional rollercoaster and in the hard times I reminded myself that I was lucky to be alive. I would hardly sleep at night, replaying the last few days and crying about the unbelievable events. It was a surreal experience, because as much as I was sad, I was also so grateful that my parents survived the crash and we were ok.

My family tried to help by reaching out to people they knew, who knew someone who had a colostomy. I was scared to eat and I wanted firm direction on what would not create issues. There were support groups, but I didn't feel like I would fit in there. I was able to connect with a young woman who had a colostomy and it gave me so much relief. Just knowing somebody else similar to me, someone who had dealt with a colostomy, meant the world. I also incorporated exercise, which made me feel good.

After just a couple weeks I started a Masters program and I was back to work. I remember those days being very stressful for me, because I worked in an office setting, which was quiet. My stoma made noises at unpredictable times. It became a bit of a game for me, constantly changing my eating habits, not eating at all, just to get it right. Thankfully, I lived close to work, so I was able to go home to change my bag, but I used a black sock to hide my supplies in case I ever needed to change while at work. There were days I felt defeated and helpless. I was forced to learn how to manage a stoma, and fearful that my body would never be the same.

At 25, I came under a lot of peer pressure to carry on with my usual social scene. I tried, as best as I could, to distract myself. I found that being open to my situation with people helped ease the embarrassment of the colostomy. I talked and talked in an attempt to sort through my confusion and spinning head. My two roommates at the time were rocks. My friend talked me into going to a Halloween party. Wearing the costume I felt no one would know I had a colostomy and I didn't touch any food to avoid any noises. One particular weekend I took an overnight trip to a football game. I remember meeting a group of guys, and being so scared they would notice my stomach.

The day of the reversal felt like Christmas. It seemed that I had been waiting an eternity, three months to be exact. By mistake I 'Googled' colostomy reversals and found a lot of horror stories. I tried to tell myself that my story would be different, and I leant on my sister for support. All my friends knew how much I wanted it gone; we had a 'Tight and Bright' themed party planned to show off my new stomach. I'll never forget driving to my parents that day. I got a call from my insurance company regarding the fact that they were missing some necessary paperwork, something that would delay the surgery. The worry of not getting the reversal crept in like a freight train and I became dizzy; I pulled over, right then and there, and wept. However, the operation did go ahead.

Four years since my reversal, I find that I'm still learning about nutrition to improve my overall quality of life. The scar tissue in my colon has created problematic digestion. Periodically I still experience excruciating pain resulting in hospital visits for partial bowel obstructions. Most recently I decided to leave home to travel abroad. Within a couple weeks I found myself in a backpacker in New Zealand suffering from acute abdominal pain, a result of a hectic schedule and a traveler's diet. Being thousands of miles away from home, I had to be my own problem solver. My new international friends couldn't understand my situation, so the recovery was up to me. This is the sort of situation that keeps my lifestyle in check and pushes me to live life to the fullest. I'm looking forward to seeing first hand how other people in different countries live their lives. I think it will bring a lot of new perspectives to my own circumstance.

Through all this, I have become a certified spinning instructor, opening my own studio back at home. Just five months after my reversal I ran a half marathon and have run others since. I believe in the power of pushing my body past its faults. I'm grateful for life. I'll always have my scars and experiences and these strengthen my ability to persevere and solidify the importance to live my version of the best life.

Tara Lonneman

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THE IMPORTANCE OF WILLS

If you have not yet made a Will, you are not alone. Even though it is probably the most important document you will ever produce as it protects and distributes your assets on your death in accordance with your wishes, 60% of the population don't have one.

Rachel Fuller
Royce & Co, Solicitors

It seems that we suffer from the ostrich effect when considering writing our Wills and that we will be struck by a bolt of lightening as soon as we sign on the dotted line. This could not be further from the truth and it need not be a daunting process.

The wording in some Wills can be off-putting and complicated which makes the task of contemplating what will happen to our affairs once we have shuffled off our mortal coils all the more daunting. However, solicitors and Will writers are trying to make the language less complicated, even though the precedents are decided by law and the language is part and parcel of that. The key is finding someone who can prepare a Will for you and explain exactly what the clauses mean.

There are various misconceptions if you don't make a valid Will along the lines of: "I don't have anything to leave anyone", " it's too expensive" and "my family know everything should be divided between them equally". Together with the ill-conceived idea that if you write on the back of a shopping list what your wishes are, everything will be fine, can cause untold stress for your loved ones.

If you do not make a valid Will, your estate will be divided out in a standard way set out by law which means that:

- your estate could be administered by someone who you haven't seen in many years just by virtue of the fact that they are a distant family member;
- if your children are under the age of 18, the court would appoint guardians to look after them who may not be the people you would have chosen yourself;
- unmarried partners may not receive anything from your estate unless you have made a Will including them;
- your spouse or civil partner may not receive as much as you would like if you have children as well; your children might not receive anything at all!
- if you just have parents and siblings, they may inherit your estate even if you would prefer it to go elsewhere;
- those close friends who have been so good to you over the years do not receive any token of your appreciation you may like to leave them; and
- any charities you would like to benefit would not receive a penny.

This can lead not only to stressful situations with family members and close friends who have been promised the family silver, but possibly a higher inheritance tax bill as a Will can often assist with the tax planning process too.

So what does a valid Will allow you to do?

- To note any funeral wishes you may have;
- leave clear instructions about how your estate is to be distributed. We have full testamentary freedom in the UK allowing you to leave your affairs to whomsoever you wish;
- to choose your executors (the people who administer your estate) as long as they are over the age of 18;
- to appoint guardians for your children if you die when they are under the age of 18;
- to make specific gifts or cash donations to family members, close friends or charities; and
- if you have children from a first marriage, you can arrange for your entire estate to pass to your children subject to your spouse having the benefit of your estate during the remainder of their life.

How do I make a valid Will?

The obvious answer is to get in touch with a solicitor or Will writer who can do it for you. Although you may have to pay for your Will, you will be assured that your Will has been correctly prepared, validly executed and your estate will pass to those whom you wish it to pass easing the stress from what will already be a tough time for your loved ones.

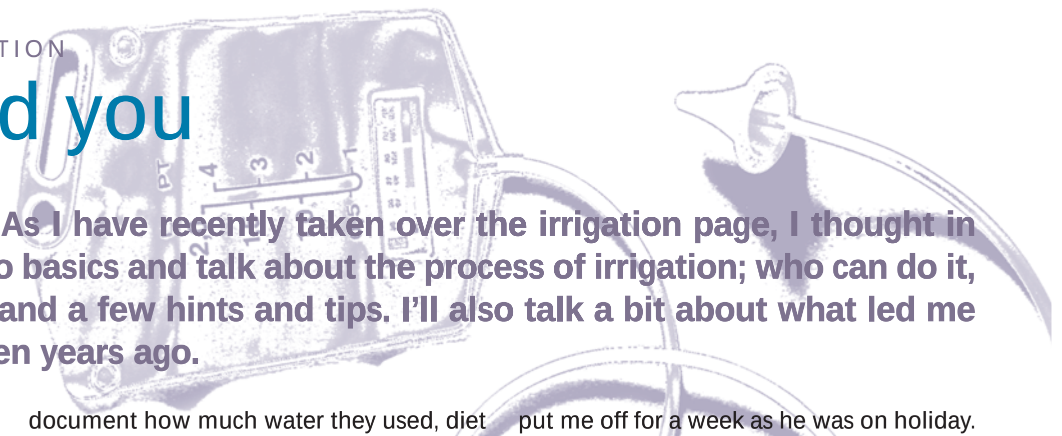
If you wait until November and are 55 or over, you could get a free Will drafted by a solicitor as it's Free Wills Month. The scheme covers simple Wills so if you think you need something a bit more complicated, the solicitor will ask you to pay a contribution to cover the extra time.

Further information can be found about solicitors who are offering this free service on page 45. Be brave and take the sensible step towards making a Will. It will greatly benefit the loved ones you leave behind and give you peace of mind in the interim. Remember, a Will can be updated at any time if your situation changes.

Rachel Fuller

In our next issue, Rachel looks at *Lasting Power of Attorney*.

Irrigation and you



Sarah Squire, Trustee writes: As I have recently taken over the irrigation page, I thought in this edition I would go back to basics and talk about the process of irrigation; who can do it, why you might want to do it and a few hints and tips. I'll also talk a bit about what led me to trying irrigation nearly seven years ago.

So what exactly is irrigation? 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. A long plastic sleeve is worn over the stoma and hangs into the loo so that the waste can be flushed away. The aim is to empty most of the colon which should result in no output between irrigation sessions.

You will either sit on or next to the loo – I bought a folding deckchair in Argos just for irrigating and am very comfy! The kit includes a water bag which is hung at around shoulder height and is filled with warm water. A tube comes from the bag and has a soft rubber cone at the end that is gently inserted into the stoma. Remember you have no nerve endings in your stoma so you don't feel it. The bag has a flow regulator so the water rate can be adjusted as you go, the idea being to slowly introduce enough warm water to encourage the bowel to contract and empty.

You will have lessons with your stoma nurse who will advise on water volume, but you will learn to feel when you are 'full'. The cone is then removed and you can relax for a few minutes – read a book, nip onto Facebook or crack that next Level on the Candy Crush game! During this time the bowel will contract and its contents empty down the sleeve and into the loo.

Some people find it better to instil the water in 2 sessions but only using the amount of water that is recommended for them. Remember we are all different and your stoma nurse will help you find what suits you, but you will also adjust the technique over time to work well for you. You will learn to feel once all the water and waste has emptied, then you can clean up, pop on a cap, bag or maybe use a plug and that's it hopefully until the next session.

It does take time for adjustment to irrigation and there may be some 'breakthrough' during the first few weeks which should settle. Some people suggest using a diary to document how much water they used, diet etc. Obviously this would not be suitable for everyone! The whole process takes around 30-60 minutes. It may seem a large time commitment, but for me the peace of mind was well worth it – I use the time to catch up on emails, and even write a Tidings article or two!

Some people only need to irrigate every 48 hours but as I keep saying, we are all different. Lots of things will affect the time we remain output free. Diet can have an influence – I know if I eat too many peas or drink red wine I will speed things up. I have a pretty fast transit time anyway so I am happy to irrigate each day and feel confident I will have an empty bag. Yes, I still use a bag – even after seven years I am too scared to use a cap. Very silly really but I like the reassurance that if any upset happened I am prepared.

Who can irrigate? The first step is to speak to your stoma nurse. Many people with a colostomy are able to irrigate, but there are some reasons which may mean it is not an option. Your stoma nurse will be able to discuss your individual situation and advise if irrigation is something you can try. Of course some people are able to irrigate but choose not to. You may have a very predictable stoma or just be happy with the traditional methods of bag changing. This is completely fine – there should be no pressure for someone to try irrigation if they don't want to.

All we at the **Colostomy Association** want is that if a person is able, and interested, they should be able to give irrigation a go. But there are also those of us who are a bit interested but uncertain about how to do it, what it involves and how much of our day it will take up. I definitely came into that category. I was a member of the Ostomyland forum and watched discussions on irrigation but kept putting off trying as I thought it sounded fiddly, messy and time consuming. I liked the idea of no output in the bag though, especially as my bowel was busiest just as I got to work.

I ummed and ahhed for quite some time before contacting my stoma nurse, and then was almost grateful when he had to put me off for a week as he was on holiday. But finally the day came for my first lesson. I was taught by Simon Turley in Oxford and he was brilliant.

Poor chap squeezed into a teeny loo at the hospital with me. He even had to hold the water bag up as there was no hook, and oh dear I did regret the chicken korma the night before! But having said all that it worked really well, taking about 40 minutes in all. The feeling of an empty bag for the rest of the day was amazing.

Over the course of that week I had two more lessons with Simon and although it still felt like I needed four hands I felt ready to go solo. I had my hubby on standby for my first time at home but once I tried it a few times I found that two hands are actually enough!

Irrigation isn't messy but I must admit accidents do happen occasionally, all down to operator error though. I have been known to tip warm water down me instead of into the water bag. Worse than that though is when I was all set up to watch *The Great British Bake Off* on TV through the mirror on my en suite door. I'd infused the water into my stoma, pegged the sleeve shut at the top and settled down to watch when an odd smell caused me to look down. Oh my word, I had not put the sleeve into the loo and was now surrounded by a very muddy puddle! Where do you start? Thankfully my 11 year old Maddie was upstairs with me, so she was sent off for kitchen roll, bin bags and bleach spray! The deckchair and my feet were then washed in the shower, the floor cleaned and then cleaned again to be sure, and we still made the start of the show!! You have to laugh about these incidents, especially as it is always me at fault. I now check very carefully that the sleeve is where it should be.

As a scientist, I entered into learning irrigation wanting to know exactly how long it would take, how much water I would need and how long I'd be output free. Unfortunately it isn't a science but from experience I can tell you, you will learn to know your own body and will hopefully soon settle into a routine which works for you. Don't be put off if it takes a few weeks to settle – it can take a while to get to the point where you get no output but hopefully your bowel will learn you are in charge now.

I asked the CA Facebook group if they had any tips they wish they'd known before they started irrigating. The first thing an irrigator will say to someone starting out is **RELAX**. If you are tense the bowel seems to go into hibernation, so try and be calm and relaxed. Don't irrigate if you have a tight time constraint. I irrigate in the evenings as the worst thing that'll happen is I will get to bed a bit later, but if I was clock watching to get to work I'd worry and tense up. Irrigate at a time which suits you. It is best in the beginning to stick to a similar time each day but once irrigation is working well you can move it to suit your day. My bowel always worked in the mornings but now happily cooperates in the evening, and if I have a night out I will irrigate in the afternoon or morning – **I am the one in charge!**

Have a jug handy, or as Ian J from the Facebook group suggests, an Oasis fruit juice bottle as it has a wide neck. Then you can rinse the sleeve during the process and at the end to get all the waste down into the loo.

Richard T uses an irrigation pump instead of the traditional gravity water bag. He points out that for those with limited dexterity the pump will infuse the water at a steady rate without having to manually adjust the gauge. The pump is not currently available on prescription though so it is probably best to try the normal kit first, but if you have problems the pump may be worth looking at.

Gill C and Rosemary T remind us to keep hydrated. If you are dehydrated the bowel will suck in the water in a flash so make sure you drink plenty for a successful irrigation. Pauline M says not to let space in the bathroom put you off. She has the tiniest loo separate to the bathroom and manages just fine – in fact she doesn't know what to do with herself faced with a big room.

My tip on travelling is to use bottled water in countries where tap water is not safe to drink. I take a travel kettle to warm some and then add it to room temperature water to make it just right, plus a hook or coat-hanger to hang up the water bag.

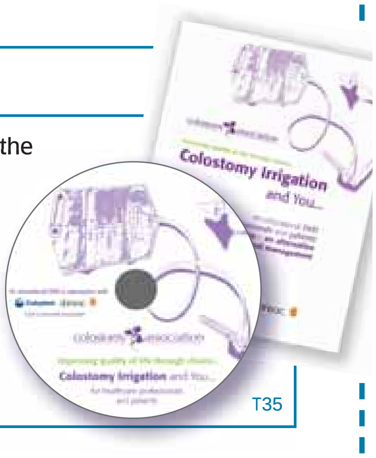
On the subject of temperature, the water must be warm. Published literature states 37°C, although anecdotally we hear that water a little warmer may work better for some people. I was told to hold my hand in the water – if it's comfy it's OK. **But do not use hot water – you could damage the bowel.** Always test it using your hand or some kits have a thermometer built in.

A letter into the office from Margaret D suggests using Milton tablets or liquid to clean out the irrigation kit. This is a fab way to keep the kit clean – it can get a bit mouldy but a soak in Milton does the trick.

I'd like to thank all those who gave hints and tips, I'm afraid I couldn't get them all onto the page but there are some very enthusiastic irrigators out there all willing to share their experiences. The **Colostomy Association** has a list of volunteers with experience of irrigation who would be happy to chat to anyone thinking of trying it or to help answer any questions. Don't forget the **Colostomy Association** have also recently launched the ***Colostomy Irrigation*** *and You* **DVD** – a great tool for explaining irrigation, including a full demonstration of the method by our brilliant volunteer Judy. I am always happy to hear from irrigators with questions or their experiences or tips so please get in touch via the **Colostomy Association** office. **Happy irrigating!**

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 (inc postage and packing) simply fill in your details below and return it with your cheque made payable to the **Colostomy Association**, to:
Colostomy Association, Enterprise House, 95 London Street, Reading, Berkshire RG1 4QA

T35

Title:

Name:

Address:

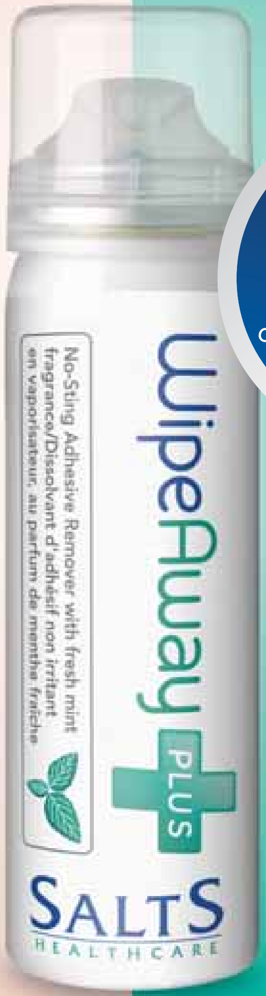
Postcode:

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

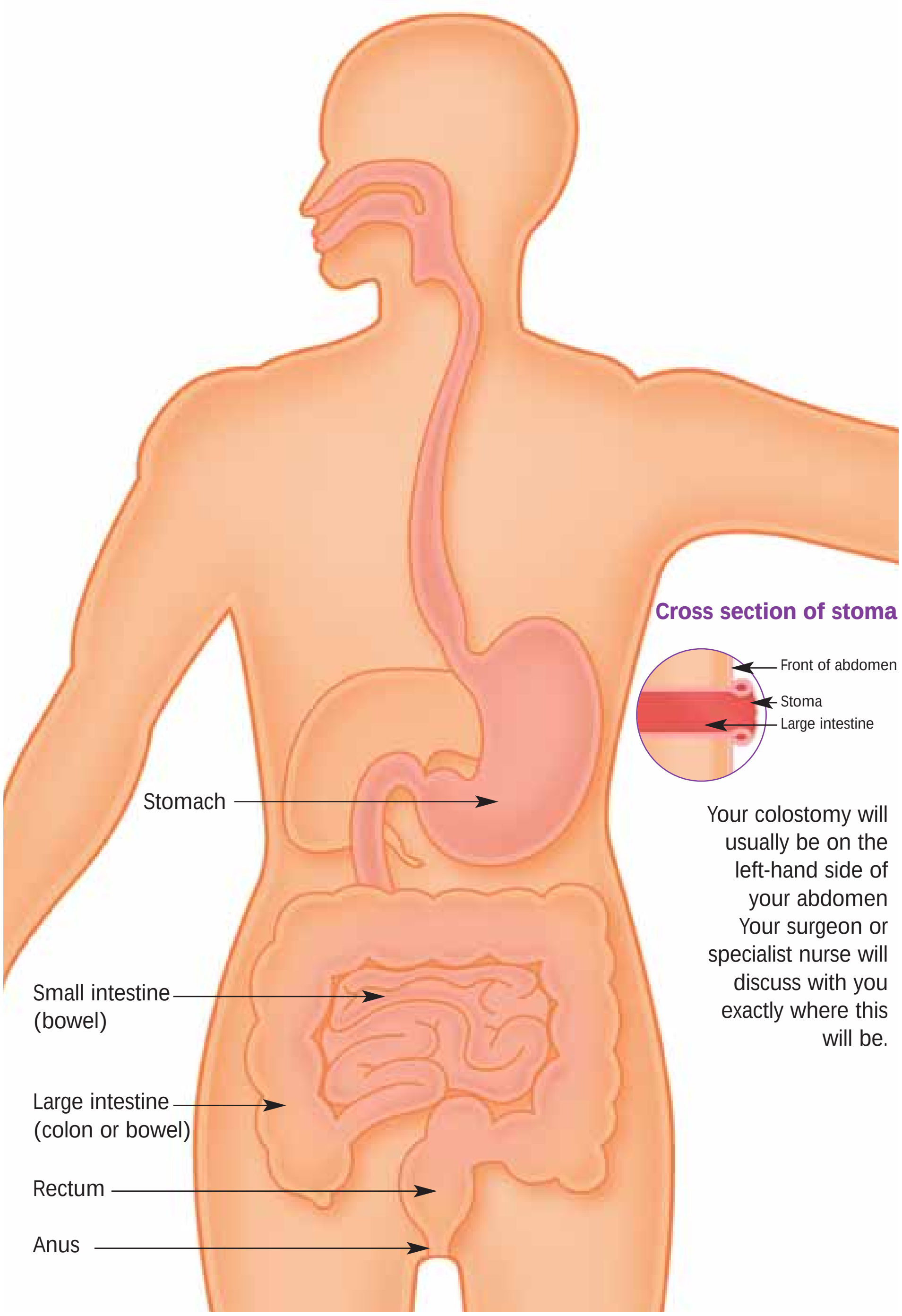

WipeAway PLUS
No-Sting Adhesive Remover with fresh mint fragrance/Dissolvant d'adhésif non irritant en vaporisateur, au parfum de menthe fraîche
SALTS HEALTHCARE

I have a Colostomy because…

The editorial team demonstrate that there are numerous reasons for forming a colostomy. Both Sue and Jackie had theirs following surgery for bowel cancer. Sarah's stoma was due to a recto-vaginal fistula.

Georgina's was necessary because of Crohn's disease and Duncan had his following a freak accident where a faulty flare, that he was demonstrating for a sailing DVD, exploded in his abdomen. My problem was a rectal prolapse that several operations had failed to repair.

Rosemary Brierley



Your colostomy will usually be on the left-hand side of your abdomen Your surgeon or specialist nurse will discuss with you exactly where this will be.

Tell someone you have a colostomy and the chances are they'll assume it is the result of bowel cancer. In two out of three cases they will be right. But what about the other third of colostomates? Why were their stomas formed?

There are many different medical conditions that can lead to a colostomy.

Diverticulitis

10% of all colostomies are formed because of the complications of diverticulitis. By the age of fifty it is estimated that half the population will have diverticula, small bulges or pouches, protruding from their colon (large bowel). This is known as diverticulosis and in most cases will not cause any symptoms.

However, one in four will experience pain and bloating and be diagnosed with diverticular disease and treated with a high fibre diet. If the diverticula become inflamed or infected this is known as diverticulitis.

A very small minority of people with diverticulitis will require surgery to remove part of the colon, and for some a stoma will be necessary. This may be temporary to allow the bowel to heal or if a large section of the bowel has been removed it can be permanent.

What about the remainder

This encompasses a wide range of diverse medical conditions, none of them accounting for more than 4% of all colostomates, some much less.

Inflammatory bowel disease includes Crohn's disease and ulcerative colitis. In both these conditions the intestines become swollen, inflamed and ulcerated, and this leads to symptoms of abdominal pain, weight loss, tiredness and diarrhoea, sometimes with blood and mucus. These conditions can be controlled with medication and can go into remission, but if the disease is severe and doesn't respond to treatment a stoma may be the answer.

Ulcerative colitis only affects the colon (large bowel) and rectum so an ileostomy will be formed because removing the whole of the colon and rectum eliminates the possibility of further attacks of colitis. Crohn's, on the other hand, can affect any part of the digestive system so a colostomy may be formed.

CONTINUED ON PAGE 29, COLUMN 1

TOGETHER

we can make it

EASIER

Medilink is more than just a stoma care home delivery service. It's your personal network of advisors, drivers, packers, Stoma Care Nurses and ostomists, all **working together to offer help and support**.

We will understand and remember your needs, **always being there at the end of the phone. Come in to meet us at one of our Customer Care Centres and find out why *it's good to be part of Medilink.***

SALTS medilink
Together we can make it easier

FREEPHONE
0800 626388
or visit www.salts.co.uk

CONTINUED FROM PAGE 27

In the case of both diverticulitis and inflammatory bowel disease a stoma may be formed during emergency surgery because there is concern that the bowel will perforate, or indeed, it has already ruptured, leading to peritonitis. However, the bowel may also perforate for other reasons including an obstruction and abdominal trauma as a result of an accidental injury such a road traffic accident.

Not all colostomates are adults

Babies born with bowel deformities may require surgery which involves creating a stoma. One in 5,000 babies is born with Hirschsprung's disease where nerve cells are absent in the rectum and lower part of the large bowel. This means this section of the bowel is unable to relax so motions cannot be passed and they build up to form a blockage. Imperforate anus is where the opening to the anus is missing or blocked. In both conditions surgery is required to correct the defect and a stoma formed to allow the affected section of bowel to recover.

Saving life or improving quality of life

In all the conditions mentioned so far there has been no choice whether or not to have a colostomy; a stoma has been a life saver. There are, however, situations where a stoma will be suggested as a means of improving the quality of life.

There are various treatments for bowel incontinence, but if these all fail then the sufferer may opt to have a colostomy. Once they have recovered from the surgery many say they are pleased they decided on this option as they are now able to go out without worrying about 'accidents' and live life to the full. In women the primary cause may have occurred during childbirth when the muscles controlling the bowel were damaged; bowel incontinence may have gradually got worse and only become a problem many years later.

Other reasons for creating a colostomy can include a fistula (an abnormal channel linking two loops of intestine or the intestine to another organ or the skin), a rectal abscess or a rectal prolapse, but these stomas are often temporary to allow the bowel to heal following surgery.

People with conditions where the nerves to the lower bowel are affected ie. spinal injuries, spina bifida and multiple sclerosis may opt for stoma surgery. This is usually where there is a problem with chronic constipation or severe bowel leakage, which cannot be managed by other means.

We are all different

Although we all have stomas the reason we came by them will vary. This partly explains why our stomas behave differently, why some ostomates can eat anything whilst others find it is best to avoid certain food, and why some of us experience more problems than others.

Stomas seem to have become a hot topic in the newspapers and on the internet just recently. So if ever you are talking about your stoma and are asked why you had it, don't forget to mention that yours is just one reason: there are many, many more.

Organisations providing information and/or support for medical conditions which may lead to a stoma:

Cancer
Macmillan Cancer Support
www.macmillan.org,uk
Tel 020 7840 7840
Helpline 0808 808 00 00

Beating Bowel Cancer
www.beatingbowelcancer.org.uk
Tel 08450 719301

Bowel Cancer UK
www.bowelcanceruk.org
Tel 020 7940 1761

Diverticular disease
www.corecharity.org.uk/conditions/diverticular-disease
www.nhs.uk/conditions/Diverticular-disease-and-diverticulitis

Crohn's Disease & Ulcerative Colitis (Inflammatory Bowel Disease)
Crohn's and Colitis UK
www.crohnsandcolitis.org.uk
Tel 0845 130 2233

Hirschsprung's Disease
Hirschsprung's & Motility Disorders Support Network (HMDSN)
www.hirschsprungs.info

Incontinence
Bladder and Bowel Foundation
www.bladderandbowelfoundation.org
Tel 0845 345 0165

T35

Photo ID Card

The CA 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 CA for processing with the various enclosures listed below:

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

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

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

Please allow 10-14 days for delivery – thank you

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

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

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

National Key Scheme - Key and photo ID card purchase

Title: ________________

Name: ________________

Address: ________________

____

Postcode: ________________

Tel: ________________

Email: ________________

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

Please **tick** as appropriate:

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

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

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

Signature of self or carer: ________________ Date: / /2014

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


trio Silex™
silicone – flange extender
www.trioostomycare.com
trio Silvex™
silicone – convex seal
2
TR 1030CX
30mm - 40mm
Contents: 10 Units
trio Siltac™
silicone – ostomy seal
3
TR 1035
35mm - 44mm
Contents: 30 Units
trio Silken™
silicone – stoma gel
TR 1070

Ostomy Lifestyle update

Ostomy Lifestyle is headed up by Sue Hatton as Chairman, and several other new Trustees have been welcomed to the Board, giving the Charity fresh dynamism and some exciting plans are afoot to develop their existing services even further – for the benefit of urostomates, ileostomates, colostomates and their carers alike.

L-R: Two fellow runners, Helen, Hannah Gagen, Rachel Viel, Alan Summer, Dani Thomas

OstomyAid

In July we reported how OstomyAid was continuing to provide desperately needed stoma supplies to people in developing countries and how much the project relied on its wonderful team of volunteers to do the sorting and packing.

Sadly, in August the landlord gave notice to vacate the premises in Bracknell which had been leased at a discounted rental for several years. This has meant that this incredibly worthwhile project has had to be put on hold and no further donations are being accepted as all the items have had to be put into short term storage.

All the stops are being pulled out to try to find suitable alternative premises so please continue to keep any unwanted stoma items, particularly one piece closed or drainable pouches, matching two piece pouches and clips. These items will be urgently needed when the project re-opens its doors so your assistance will be greatly appreciated!

It is hoped that **OstomyAid** will relaunch later in the year so look out for further updates via the website and in *Tidings*.

It is worth noting that if you have any unwanted medications a charity called *InterCare* based in Leicester take a variety of different products which include prescription medications and nebulisers.

Once a GP registers with them, the charity arrange collection of items from the GP surgeries.

They can be contacted on **0116 269 5925** or to find out more about what they do please visit their website at **www.intercare.co.uk** as their list of acceptable items changes regularly depending on the needs of their recipients.

This summer one of the Ostomy Lifestyle Trustees, Hannah Gagen, took part in the British London 10K to fundraise for OstomyAid and she exceeded her target by raising £1,096.00.

Hannah became a Trustee in 2013 having had her ileostomy operation in 2009. During that time she has also been an active fundraiser for the charity, mostly through a variety of sports.

Hannah works in the pharmaceutical sector and has a background in public relations, lobbying and creative industries.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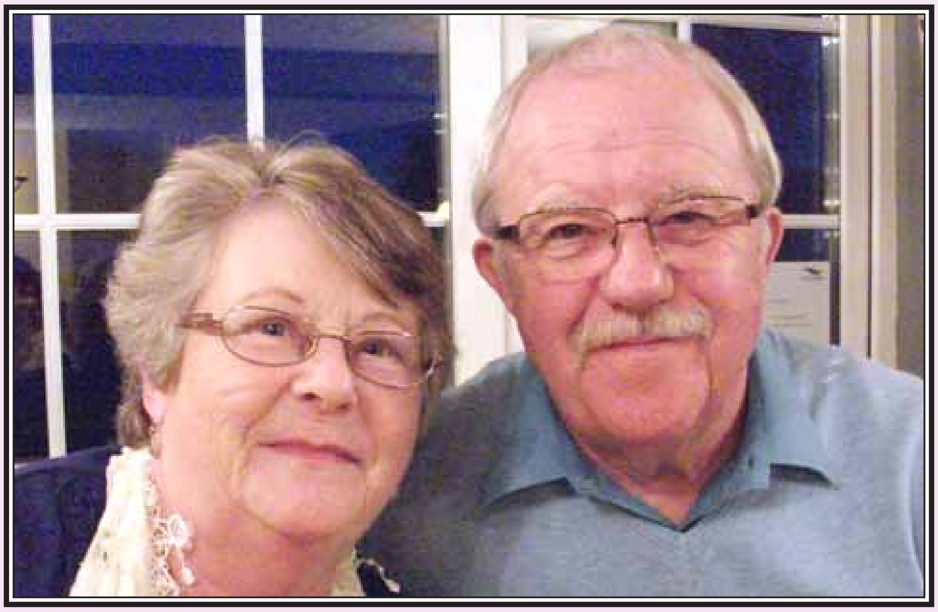
No sting
No cold propellant
Use any way up
clinifilm
Non sting
No cold propellant
Sprays any way up
peel easy Medical Adhesive Remover Wipe
clinifilm Skin Protective Wipe

Coming to terms with a Colostomy

Bob Williams found writing his story for *Tidings* was cathartic; telling all this has given him a welcome release. He was able to write about issues which he has never spoken of before.



Bob says: "Every ostomate - a name that reduces the condition to something shared - develops their own routine for life with a stoma. I would like to offer my own experience. If only one person finds some direction or help from this, that's a bonus."

But first a little background…

I am Bob, 69 years old and married to Dianne, my soul mate, to whom I owe so much. Her support and help during those times that ostomates will recognise as 'accidents' has been marvellous and I am really blessed to have her at my side. I have been a merchant seaman, a miner, a soldier, a mechanic and a workshop foreman. Then disability, the result of an industrial accident some years previously, caused me to look for less strenuous employment. I retrained in business and managed to find a job in local government, but later was forced to retire on health grounds.

I had been suffering from a crushed No. 4 vertebra, which was impacting upon and damaging spinal nerves, causing numbness and paralysis. I was told that, without an operation I would most probably be a quadriplegic. That kind of information concentrates the mind and I had a successful back operation in late 2009. Although my left side is still weak and I walk with an orthopaedic crutch to prevent falls, I can walk and I no longer have any paralysis or numbness. I bless that surgeon every morning when I wake and get out of bed unaided.

From 1969 onwards I had also been suffering from haemorrhoids, and had undergone three operations to cure them; in fact, as my story will explain, there was no cure. I endured occasional bouts of abdominal pain, diarrhoea and constipation.

We continued with our lives but my abdominal problems grew gradually worse. I was now visiting the toilet two or three times a day and the pain was increasing. I reached a terrifying point which involved me actually pushing my rectum back into my body. I could not bring myself to tell anyone about this. I had been in some bad places in my life but I think this was my lowest point, the most fearful time of my life and I was keeping it hidden, even from those I loved. Eventually in 2009 I suffered an agonising prolapsed bowel. I laid in severe pain and discomfort from 9:30am to 4:45pm. Then an ambulance rushed me to Grimsby hospital where I underwent an emergency colostomy.

The aftermath will be familiar to ostomates. Until I developed a routine (and occasionally afterwards) I had all the usual accidents. But my logical, organised brain, a relic of 12 years in the army, gave me the ability to look beyond any misery I felt and devise a coping strategy. My wife, son, daughter and four grandchildren, have all been supportive and I love them all more than I can say. Which brings me neatly to our youngest, Eleanor, who was five years old at the time of my operation. The family came to see me a few hours after I came out of theatre and I was attached to the usual pipes and tubes. My daughter must have explained what had happened to granddad in terms that a five year old could understand, because a couple of weeks later at home, Ellie sidled up to me on the sofa and whispered in my ear, "Granddad is your pipe all right now?" You can imagine my reaction: a mixture of amusement and emotional response that filled my eyes with tears.

I have a large parastomal hernia and I could not get any of my trousers to fit, then I found the online clothing service from Chums **www.chums.co.uk** and found high waist trousers and shorts. I rebuilt my wardrobe and gave away my previous trousers to family and charity shops. Then I once more set about coping with this new presence on my left side. I looked into diet and noted my daily foods and recorded my body's reaction to each meal. Any flatulence, odour, loose or solid stools were noted and I worked out over a period of weeks and months that it was best to avoid peas, sweetcorn, broad beans and nuts. However this is a very individual thing and everyone finds out for themselves what does and doesn't suit them.

I ordered samples of various products from different ostomy suppliers. I found the combination that suited my stoma and my skin and I stuck with it, although I have seen a pouch in the latest Tidings which may be more comfortable for my parastomal hernia. I would like to record my gratitude here to the suppliers from whom I have requested samples over the last five years. Thanks guys 'n' gals you are part of every ostomates' life.

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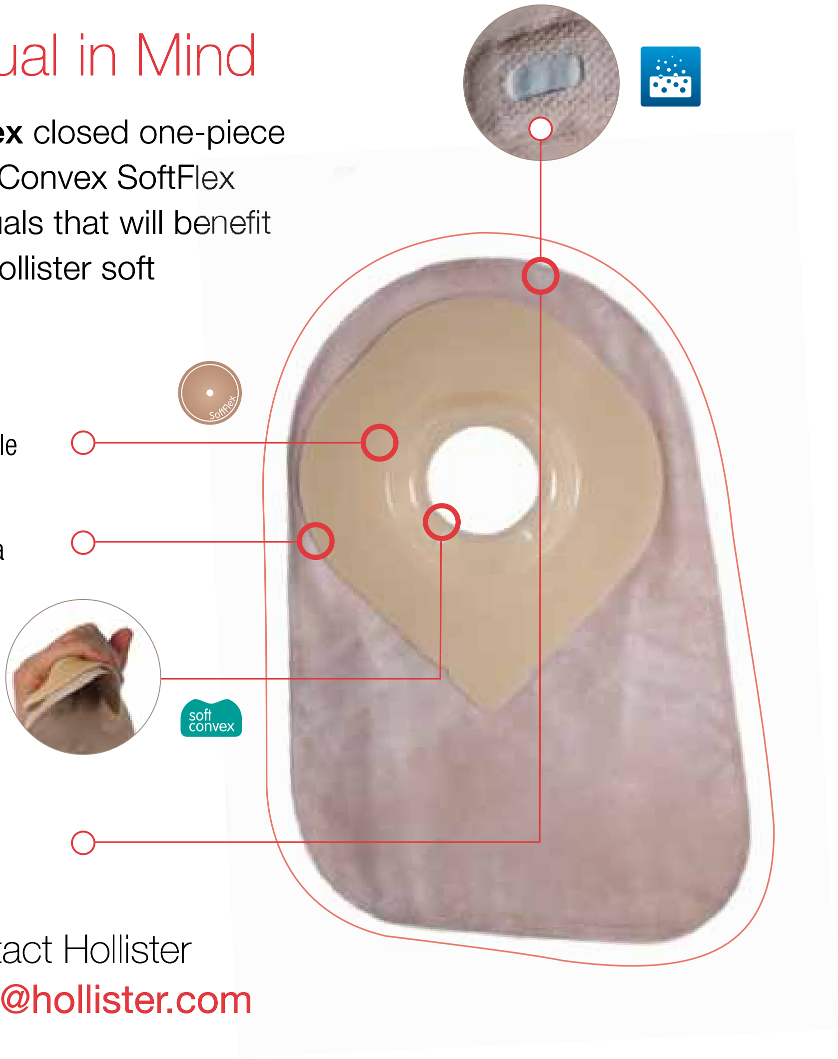
SoftFlex
soft convex

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Below is my usual morning routine, the ways and means I have developed to make dealing with a stoma easier. I hope this helps someone else. After getting up in the morning I usually find that my pouch is practically empty, This is assisted by eating my last meal in the previous evening as early as possible: I find that 7pm is best.

I eat my usual breakfast of wholemeal toast (perhaps a little honey) a Weetabix and a small glass of orange juice with the juicy bits – I find this helps to get things moving! A read of my current book whilst things develop within the pouch, then into the bathroom. Shave, brush teeth, shower and change the pouch.

I have come to realise that a dry, clean skin surface around the stoma is essential to keep my skin free of soreness and inflammation. Also I have a hairy body and I have to carefully shave the area around my stoma every two weeks or so, in order to help the pouch adhere to my skin.

I prepare my bits and bobs for the change in the same way every time: it helps build up a routine. I place a can of deodorant spray alongside my adhesive remover. One dry wipe goes into a sink of hot water and one is kept to dry around the stoma before attaching a fresh pouch. This in my case is a convex one-piece with belt hooks. I place a disposal bag at the ready with a doubled sheet of toilet paper inside the bottom of the bag to keep it open.

I kneel in front of the toilet bowl and use the adhesive remover to remove the full pouch. "Why kneel?" I hear someone ask. Well, because I have had accidents over time. I call these oozers or splatters depending on the way they issue forth. Kneeling in front of, and over the bowl, I can direct any offending material directly into the bowl to be flushed away.

I have a heater-blower fan in my bathroom so after I have cleaned and blotted the stoma area with a dry wipe I can stand under this while I dry off. Then I wash my hands and fix a fresh pouch, taking care to line it up correctly with the outline of my stoma. I press it down firmly with my hand for ten seconds and then attach a belt to the hooks. I am aware that not everyone uses a belt. In fact I only wear it for about an hour, or until I am sure that the pouch is safely fixed, then I remove it.

I place the used pouch into the disposal bag, spraying the room and the inside of the bag with deodorant. All wipes go into the bag, putting them into the toilet asks for a sewer blockage! I try to squeeze out air from the bag then tie it tightly as far down the neck of the bag as possible. In my village there are several dog-poop bins. I was informed that this is incinerated. I really dislike putting my waste into the domestic bin which is what the council advises, so my waste joins the dogs' poop.

I sincerely hope that some of the methods I use can be of help to others, but please remember that my own routine may not be suitable for everyone.

This is my story. I was not always so blasé about dealing with life as an ostomate. In fact at first I was just down and depressed with the Why me? syndrome. At the time I had a 91 year old neighbour who heard of my problems and summoned me - Kath was not a lady to be refused. I got a real dressing down. She told me to buck up my ideas for the sake of my family and that she had been using a stoma bag for over 40 years, since the days of rubber bags! It was exactly the kick in the pants I needed. It helped me to understand that my family were suffering, not just me. Thank you Kath, you will never be forgotten.

So I say to new ostomates: "Yes it may look bleak now, but there are more than a hundred thousand of us in the UK and we all find a way to get through this and have a good life. You are not alone."

Bob Williams

New Parent Helpline

Junior Ostomy Support Helpline

A new parent helpline called JOSH is being launched this autumn at the Association of Stoma Care Nurses (ASCN) conference in Harrogate.

This project has been well received by members of ASCN and paediatric stoma care nurses (PSNG), a former Trustee of Breakaway and a young ileostomate who highlighted how vital it is to have professionally trained people to provide support.

This helpline is available for parents or carers of children with a bowel or bladder diversion/dysfunction and the volunteers will be offering practical peer support.

A select group of parents/carers have been trained at our offices and they are ready to take calls. Niamh Geoghegan, a PSNG, is on the JOSH committee, along with Helen Bracey and Wendy Hetherington, and they have led the training course.

Successful training of parent volunteers by Niamh

This dedicated team of volunteers has a wide range of experience surrounding children's continence issues and they will be helping other families in similar situations. This is not a medical advice service and anyone with medical queries will be directed back to their health professional.

This service will operate through the **Colostomy Association's** 24 hour helpline and our operators will pass on referrals by matching them to one of the JOSH parents.

It will be vital lifeline to carers when they are at their most vulnerable and will redirect callers to Breakaway or Diversions where appropriate.

Training of additional volunteers will be ongoing so if you are a parent or carer of a child in a similar situation and would like to be considered for this role, please contact Sue Hale on the number below.

Please call **0800 328 4257** if you'd like to speak with a JOSH volunteer.

Dreams do come true

On 11th June this year my dream came true when I finally married my partner of nine years, Richard. It was a day that I never ever thought would come after I was diagnosed with an inoperable cancerous tumour in my sigmoid colon in December 2010. I was 49.

I had been feeling poorly for ten months up to then and had been going through all sorts of tests to try and find out what was wrong with me. I had been sick, lethargic, no energy and lost three stone without trying to. Finally a CT scan revealed the tumour and we were told in early December 2010 that no surgeon would attempt to operate due to its size and location.

Christmas that year passed us by in a complete haze but I stayed strong and remained positive that I was going to fight this. In January 2011 I started intense chemotherapy which lasted seven long months and totally drained me. This was then followed by six weeks of daily radiotherapy at our local hospital which was a daily round trip of more than 25 miles. Both Richard and my daughter, Emily, took me every day between them. The morning of my 50th birthday was also spent at the hospital having my daily treatment.

By the middle of September 2011 all the treatment had ended and a scan revealed that the tumour had shrunk considerably and that they were finally going to attempt to operate. Both Richard and I burst into tears at this news but these were tears of happiness this time. The operation was scheduled for mid-December 2011 and my brilliant surgeon said he didn't really know what he would find until he opened me up.

The night before the operation was scheduled was probably my darkest hour and I just wanted to run away and hide as I was absolutely terrified but knew I had to do it. We arrived at 7am, but by 1pm I was sent home as the high dependency bed they had reserved for me had been taken by an emergency. The operation was re-scheduled for four days later when it did finally go ahead.

I was in surgery for nine and a half hours. The tumour and all the surrounding area was removed along with the lymph nodes and sigmoid colon. I had a Hartmann's procedure, surgical hysterectomy, total oophorectomy, stents put into my urethra tubes where the tumour had been pressing on them, and the formation of a permanent colostomy.

I don't remember an awful lot about the first few days after the operation but I had tubes and lines attached to me literally everywhere. They all started to come out one by one and each day I was slowly recovering. I left hospital ten days later after my surgeon came to see me and told me that they had got everything and the operation had been a total success. It was two days before Christmas 2011.

It was a very quiet Christmas that year but so different to our previous one. I had done it!

Then started my long recovery. Learning to live with my stoma was very hard to begin with and I was frightened to eat but slowly and with the support of my fantastic stoma nurses at The John Radcliffe Hospital in Oxford we got through those first few months together. It wasn't easy but I accepted that without it I wouldn't be here and wanted to get on with my life after all I had been through. My stoma nurses (Jo Buxton, Nicky Samways and Simon Turley) gave me (and still do today) the most fantastic support. They are an amazing team and do the most fantastic job and I am so grateful to them for their continued help and support.

I was told that it takes around one month to recover for every hour that you are in surgery and it did take me nine months to recover from major surgery. By my side the whole way had been my amazing partner, Richard, my beautiful daughter, Emily, who devoted all her time to caring for me despite working full-time, and my two wonderful (now) step-children, Annie and Harry. Between all of them they got me through all of this and I am so proud of them all.

In September 2012 I finally returned to work albeit part-time but it was something I never thought I would do. I did try irrigating as I was worried how I would cope at work with my stoma but that didn't work out for me. Unbeknown to me then, I had portal hypertension and it was recommended that I didn't irrigate. Everybody at work knew about my stoma, I wasn't embarrassed and didn't need to hide it. It meant I was alive so I was in a strange kind of way almost proud to have it. I carried my change kit with me and the disabled toilet at work was cleared out for my return and I would just toddle off there if it needed changing. Nobody queried me disappearing and for that I was grateful as I could be discreet. The last thing I wanted was any fuss.

I have had a couple of problems due to the portal hypertension over the last couple of years which resulted in me having to have my stoma refashioned at the end of last year but at the moment all is settled and I continue to work full-time.

One Saturday before I returned to work, Richard and I were shopping in our hometown of Witney. He suddenly took my hand and led me into a jeweller's shop. He had been in previously to choose an engagement ring for me and in the shop he asked me to marry him! Even the shop assistant was in tears. He told me that he had wanted to wait until I was fully recovered to ask me even though he had wanted to for a long time.

So finally, on Richard's 50th birthday, 11th June this year, my daughter Emily walked me down the aisle to marry the man of my dreams. It was a very emotional day for all of us after the last few years but we were surrounded by our closest family and friends and we had the most wonderful, wonderful day. My stoma behaved impeccably and I didn't even know I had it.

The Colostomy Association were introduced to me at a stoma care open day at the John Radcliffe hospital about four months after my operation and they have been a fantastic support to me over the last few years and are an amazing organization. We asked for donations for our wedding as there were no presents we wanted and we literally smashed our target and have decided to split the donations between Cancer Research and the Colostomy Association as without either of these I wouldn't be here today to tell you my story.

So you see, **dreams really do come true.**

Anne Gray

CLOSED POUCHES

Secure solutions designed to make your life easier

Oakmed's wide range of closed pouches, as chosen by many Stoma Care Professionals, are easy to use and comfortable to wear. Our pouches provide security for stomas of all sizes, even when the pouch is cut to the maximum size, up to 3cms of adhesive area still remains, making them secure and reliable.

ALGINATE	Alginate - an adhesive which contains alginate. Promotes skin integrity, absorbs moisture, helps to heal sore skin.
HYDROCOLLOID	Hydrocolloid - a soft, flexible, hypo-allergenic adhesive.
micro skin®	Microskin - the lightest, thinnest and most flexible wafer available.
biform®	Bi-Form - a wafer combining the benefits of Hydrocolloid and Mircroskin.
connect 2®	All four adhesives are available on a two piece system.

To order your sample today

call 0800 592786 or **visit www.oakmed.co.uk**

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

The 500 club is a way of raising vital funds for the Colostomy Association and will also give you the chance to win cash prizes ranging from £25 to £1000.

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

At the end of each year a further prize of £1000 will be awarded.

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

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

500 Club June 2014 Draw Winners!

Mr D Ogden	£	307.00
Mrs J A Gilbert	£	153.50
Mrs C Denton	£	61.40
Anonymous	£	61.40
Anonymous	£	61.40
Mr M J B Taylor	£	30.70
Anonymous	£	30.70
Anonymous	£	30.70
Mrs R Penketh	£	15.35
Mrs B Lowy	£	15.35
Sister A M Eden	£	15.35

NOTE:

Mr D Ogden donated £25.00 back to CA; Mrs C Denton donated £11.40 back to CA; Anonymous donated £30.70 back to CA; Mrs B Lowy donated £15.35 back to CA.

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

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Reading
RG1 4QA

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

Colostomy Association:
Lottery Licence no. LOT000141

T35

500 Club entry form

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Bank Address: Postcode:

Name(s) of Account holder(s):

Account number: Sort code:

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

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

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

Quoting reference: **500 Club**

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

Name: (IN CAPITALS)

Signature: Date: / /2014

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Facebook Meet

Natural History Museum, 19 July 2014

Sarah writes: The CA Facebook group continues to grow and friendships rapidly develop.

Members love nothing more than to meet up in real life so as well as the CA organised meets there have been a number of "mini meets" as they are called by the group, an opportunity for a few members to meet up for a coffee, lunch or go to a tourist attraction.

Natalie Slow (the one with the tongue sticking out in the picture above) and Sally Armstrong (dressed in stripes in the picture. on the right) organised the latest event, on Saturday July 19th.

Sally writes: After last year's rain-drenched meet-up in London, Natty and I decided to play it safe and go somewhere with a roof!

Little did we know it would be one of the hottest days of the year – and of course the Natural History Museum doesn't have air-conditioning!

We met at South Kensington station, and were then confronted with quite a long queue when we arrived at the Museum – however Vicki Hobbs used her charm to get us in ahead of it – not sure the friendly girl she spoke to had any idea what a colostomy was, but it did the trick!

There were 15 of us altogether – including husbands and partners, and Lesley's sister. We took over a café area upstairs – where we all sweltered but enjoyed chatting to new and old friends.

After a look around at some of the exhibits we gathered again at the outside café, and continued the conversations – and some singing too – until we were told to leave because they were closing! A great time was had by all and we hope to get together again soon – there is talk of going to the V&A next time, so if you'd like to join us keep an eye out for details.

List of people who went:

Natty Moo; Sally and Neil Armstrong; Wendy Rogers and Hugh; Carol Pell; Vicki and Jeremy Hobbs; Tony Cutler; Ian Jackson, Janet Batho; Sarah Norton; Lesley and Janice Greening; and Win Weller.

The CA Facebook group is a safe haven for ostomates or their carers to chat to people who have real life experience of what they are going through, plus the group is closed which means none of your other Facebook friends will see your posts on the group.

New members may join with a specific problem, or just to speak to people who understand. The group is like a family, welcoming people as they join and soon answering any issues they may have.

It's not all downbeat and problem based though – members share happy times and enjoy a laugh and joke.

To find us, search **Colostomy Association** on Facebook, choose the group and click the **'join'** tab. One of the group's admin will add you as soon as they spot the request. We look forward to seeing you there.

Photos by Ian Jackson

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!

Apply for a **Guaranteed Place in Virgin London Marathon 2015**

See page 59 for entry form and details.

Great North Run 2014

We are proud to announce that **Paul Stokes** and **Jenifer Unwin** took the challenge to run the Great North Run 2014 (GNR) for the **Colostomy Association**, while **David Buckley** ran for the **Colostomy Association's** *Bob Buckley Fund*.

The GNR is a yearly event that takes place in September between Newcastle and South Shields. It was established in 1981 by former Olympic medallist Brendan Foster.

Jen (pictured below with her medal) said: "The run was great! I kept running the entire race and finished in my targeted time of 2 hours, 25 minutes. The atmosphere was great as I fully expected and the heat was actually OK as I'd had a few long runs in training when it was hotter earlier in the year so I felt prepared.

"Running over the Tyne Bridge is an iconic moment within the GNR and a personal highlight of mine from the day. During the race I saw so many people running for causes close to their hearts and it was a privilege to be able to support the **Colostomy Association**.

"I really enjoyed the race and finished with no aches or pains which was a pleasant surprise! I'm really glad that I managed to get a few more sponsors on the day and hopefully have a few more yet to come. It was an amazing experience and I'm really glad I've had the opportunity to run the Great North Run."

At the time of going to press, Paul had raised **£400.00**, Jen **£576.20** and David **£1,655.00**. Thanks so much this is another amazing boost for the **Colostomy Association**!

Help CA raise funds

For your FREE donation box simply contact the office – telephone: 0118 939 1537 or email: cass@colostomyassociation.org.uk to order yours today!

Special Thanks

A great many of our supporters kindly donate on an ad-hoc or regular basis. We're sorry we can't publicly acknowledge everyone individually in *Tidings* but here are a few examples. Our sincere thanks go to:

- Churches Together in Leeds for their kind donation of **£250.00**.
- Churches Together in Tilehurst for raising **£150.00** through their Link café in Reading.
- Wendy Rogers gave a donation in the sum of **£100.00** in July. Wendy also makes bag covers!
- Elizabeth Keenan kindly donated **£50.00** in August.

Thank you so much everyone – big or small, all your donations are gratefully received!

Post Office Donations

Mr K Davda runs the *Boston Parade Post Office* of Boston Road, Hanwell in London and he has been collecting donations for several years from his customers via a **Colostomy Association** money box which has been placed on his counter. Recent contributions amounted to **£31.70** and this is also a great way of raising our profile with the general public. Our thanks go to you and all your wonderful customers Mr Davda!

Thank you everyone for your kind donations

Hog Roast

CA Volunteer, Sandra Priestley celebrated the anniversary of her emergency colostomy operation again this autumn with husband, David, which coincides closely with her birthday.

Sandra writes: David and I held another successful hog roast on 7 September and, as ever, we were very grateful with the support we received from family and friends who made it such an enjoyable occasion. After deduction of expenses for food, drink and associated sundries, we have got a surplus of **£1292.28** to send to the **Colostomy Association** which is wonderful.

We received lots of help from several people, and we should like to particularly recognise the contributions from sister–in–law, Denise, for some delicious desserts, Ruth for profiteroles and potato cooking, the (Maidenstone) Loose Swiss Scouts for loan of tents, cutlery, tables and glasses and neighbour, Sidney, for the loan of tables and benches. My brother, Theo, was a great help with preparation and, with Denise, serving whilst others helped with clearing and washing up, as well as lending garden chairs. Mention must also be made of the important *Erections R Us* team for putting up and dismantling the tents and gazebos, and to Guy, supreme raffle ticket seller who raised **£340**. We received generous donated prizes for the raffle from various local businesses including *Pizza Express*, *Euphoria*, *Beautique* and our local pub, *The Swan Inn*, as well as bottles of wine from some of our friends. Finally, we could not have held the event at all without the expertise of our son–in–law, Simon, "the roaster" and the generosity of Crouches (Rickwoods) of Bearsted who kindly provide the hog and equipment at cost price.

Some people who were unable to attend made generous donations, which was great, and, as they say, the sun shines on the righteous, so the weather helped to make it a memorable day. A lot of work was involved in the preparation and clearing away, but the end result made it all worthwhile. Thank you everyone for making this celebration so special again!

Sandra Priestley

Sandra and David, it's very kind of you to organise this popular celebratory fundraising event again. A special thank you goes to you both and to all your wonderful helpers.

Andrew Trouton – Way of the Roses

Andrew cycled 170 miles for us in May as a thank you for the support we gave his dad, Richard. Sadly, Richard passed away two months later in the July and our sincerest condolences are extended to Andrew's family.

Andrew writes: "My motivation was two-fold. First of all, 10 years ago my dad was first diagnosed with bowel cancer and had extensive surgery at Craigavon Area Hospital in Northern Ireland.

Dad received a permanent colostomy and had fantastic support from the stoma nurse specialists in Craigavon. They provided him with the practical support he needed and via the **Colostomy Association** much of the information and guidance he needed as he got to grips with this new phase of his life.

Second, I'm 50 this year and as well as doing my bit to say thanks on behalf of my Dad it was also a good challenge for me to get fit!

The *Way of The Roses* is a 170 mile cycle route across Lancashire and Yorkshire which I set out to complete in 3 days. I choose the end of May for my trip as I assumed I might have a better chance of some good weather but alas that was not the case during half term week!

The second day was the hardest, very wet and windy and up and across the Pennies. There was truly beautiful scenery over some of the Tour de France route in Yorkshire but I have to admit I wasn't paying a lot of attention to it in the rain.

The coast was a welcome sight as I was starting to get tired but I was so pleased to have done it and the support of so many people in my fundraising made it all worthwhile.

I set myself an initial target of £1,000 but so many people have got behind this and the total donated online was **over £4,000**.

The donations have come from friends, family, neighbours and colleagues from around the world in the pharmaceutical industry that I work in. Back in Northern Ireland my Mum and Dad's Church in Tullyroan and my Mum's local Women's Institute in Moy also got involved.

The response has been truly overwhelming with many donations accompanied by very personal messages from people who have been through similar experiences.

I hope these funds will help make a difference and allow you to continue the good work you do in providing support and help at a difficult time in people's lives. I'd like to thank you for the support you gave Dad and best wishes for the continued work in the future."

Andrew Trouton

Many thanks for all your efforts on this major cycling challenge Andrew and we're so sorry to hear about the loss of your dad. If anyone would like to donate online to the **Colostomy Association** *via Andrew's webpage in memory of Richard, please do so at:*

www.givey.com/colostomya

Climbing Mount Snowdon

Martin Robbins, Colostomy Association volunteer, trekked up Mount Snowdon on Sunday 6 July to raise funds for us. Pictured here with his friend, Geraldine, Martin raised over £300 for us. Thanks so much Martin. It must have been exhausting!

Martin writes: In preparation for my trip up Snowdon, I travelled up to Betwsy-Coed on the Saturday afternoon and booked into a small traditional hotel, meeting up with an old friend who had agreed to accompany me the following day.

We set off on the Sunday morning to drive to the start leaving at about 8:30am. The weather was beautiful and when we arrived at the start car park it was already almost full. We had decided to ascend using the *Pyg track* which was considered to be reasonably difficult, but slightly shorter in distance.

Whilst we were just starting, it appeared to be fairly easy, but it soon became apparent that it was only going to get more difficult as the rocky short steep slopes were proving quite a challenge. We made our way slowly up the track, being pursued at times by fit young men and women who were making a race of it.

Needless to say, we did not join in! About two hours into the walk, the rain started, so after donning our wet weather gear, we proceeded with added caution, as some areas of rock became very slippery. We had numerous stops on the way, not only to get our breath back, but also to take on board refreshments. Luckily, the wet spell only lasted about 20 minutes so we were able to make the last part of our ascent in bright sunshine and we finally reached the summit at about 12:30pm.

Time to rest and we spent about half an hour in the cafe, talking to other walkers, and also explaining to those who asked what we were doing it for. (They saw the polo shirts we were wearing, as they were quite noticeable!) We set off again, and had decided to take a different descent route back, using the *miners path*.

This was quite a steep descent to start, but ended up at one end of a beautiful lake, which we could walk round to the finish point. We did not count on the impending bad weather, as after only being about half an hour from the summit there was more rain and, looking back, the summit was completely covered in cloud.

Back on with the wet weather gear and we very carefully descended on to the perimeter of the lake.

The weather again cleared and we continued for about 1.5 hours on far easier terrain until we finally reached the end point. This was about 4:00pm and I was feeling pretty shattered, so had a cup of tea and a 30 minute rest before we set off back to our homes, mine to Coventry and my friend (who had a 160 mile drive home) to Cumbria.

I have to say a big thank you to my friend, as without her, I do not think I would have managed it. Not only did she travel a 320 mile round trip to support me (otherwise I would have had to do it alone), but she walked with me, encouraged me and helped me where necessary when I found it difficult. She also was more than happy to wear one of my specially commissioned polo shirts!

I finally got home at 7:00pm on the Sunday evening feeling very tired but also proud of myself – that another challenge I had set myself had been achieved, colostomy bag and all. Also that I had managed to raise around **£250** for the **Colostomy Association!**

So, my next challenge is to find another challenge! To inspire me and all of us, to treat life and living as normal as the person next to you. Any suggestions?

Martin Robbins

Martin, you re a treasure! Thank you so much for doing such a gruelling challenge to raise funds for us.

Please pass on our thanks to Geraldine, your lovely friend too.

Last Will & Testament

This is what some of our volunteers had to say when asked about Wills & Probate.

A writes: Ten years ago, after an operation for cancer of the uterus that had spread to the bowel resulting in a colostomy, I was given the news that my cancer was terminal and I only had a short time to live. Once over the shock of the news and the realisation that I might not have much time to put my affairs in order I realised that the most important thing to do was get a Will sorted out.

I felt that it would not have been fair to leave my husband with the sorting out of my finances and verbal bequests. I was especially concerned that, as we had both been married before, the money from my input into the marriage should go to my sisters. I also wanted to make certain that the money that my husband had brought into the marriage should go to his sons.

It was very important to get the very best advice from a professional solicitor. I needed help to make my intentions clear so that the wording could not be misinterpreted and there was not something I had overlooked. The courts are full of cases where Wills are being challenged. Good advice is needed and need not be expensive.

I chose my husband to be my executor but I was also advised to think seriously who would take that task on if anything happened to him and he was unable to carry out that duty. I asked my solicitor about *Trust Funds* – and there are many – and then took financial advice. I made a special affidavit about my jewellery. I listed my bequests. I even added some private words for friends and family thanking them for caring so much for me while I was alive. It was a very personal thing, this Will, and I was happy that I had taken care of everything and everyone in the best possible manner.

I then relaxed – and began to get better! Don't ask me what happened or why but the cancer went away. Ten years later I am able to say that my life is full , I feel fine, my colostomy behaves well – and I feel the need to update my Will again as some of the people I have listed in my Will have passed away before me.

I shall be updating my Will, using this special opportunity to do it for free. I hope you too will grasp this opportunity and put your affairs in order.

B writes: My husband and I made our Wills a few years ago. My family is also aware of both of our personal feelings about organ donation and body disposal. I wish to donate my body to science so it can be used for research. If someone can learn something from everything that has happened to it then I would be happy. My husband knows I don't mind if it goes to a teaching hospital or cancer research, whoever can benefit from it most. So many times I have been told by doctors that the side effects I have had are most unusual. Hopefully if they can investigate they can learn from it. In a way it's not that dissimilar to wanting to pass on our experiences by being a **Colostomy Association** volunteer.

C writes: We used a company that supposedly came under the 'charity' banner. It was a set price, but the final result did not reflect the true position as to what we wanted in our individual Wills when it was reviewed by another third party and I therefore think the best advice is to be wary of 'cheap Will solutions' as invariably something might go wrong. It is important to ensure your relatives are left with a clearly defined document that leaves no doubt as to your wishes.

D writes: If you want relatives and friends to receive mementos, describe them carefully and date the list, try not change your mind. My relative left three lists of gifts in different places so I could not tell which were her last wishes. It is important that all valuation papers, certificates, invoices etc that a valuer might require are filed or at least put in one drawer, with the Will of course. If the Will is held by someone else make sure that name and address is recorded there. You do not want your executor to have to ask all the local solicitors if they have the Will. A disturbing thought - my relative died in a home; a ring she was wearing that morning was never found.

E writes: I went to a large and well known solicitors group to have a Will made out. An important part of the Will was how the proceeds were split. we wanted: 50% to go to my two children; 25% to go to my wife's Nephew and Niece; and 25% to go to charity. After making out the Will one of my daughter's died. I assumed that the 50% would therefore go to my surviving daughter. When I was checking the Will due to my wife's death, I discovered that the wording actually meant that my surviving daughter would have [not] received the 50% but just revised amount based on the whole Will. I then had to pay to get the same solicitor to change the Will. So, lesson's learned - Paying solicitors does not always mean you get what you want, it is still down to you to check and re-check the outcomes are what you want them to be. I have recently re-married and also discovered that when you marry any previous Will's are null and void.

F writes: I have made many over my lifetime and put into place my final one just this year. I consider it an essential preparation to put into place my wishes and look after my family members who are left.

What I should do next is make some funeral preparation involving the Humanist network but so far I haven‘t decided on the detail or the music.

A list of solicitors in your area offering **Free Will Month** scheme can be found at: **http://www.willaid.org.uk/**

Dear Reader

Most people when they have surgery which results in a colostomy assume that their back passage is removed or sewn up, so it can be a shock and quite frightening when they have a feeling of needing to pass stool. Some people may not get any sensation but suddenly leak from the back passage without warning. The reason for this is because the surgeon has performed an operation which leaves a rectal stump.

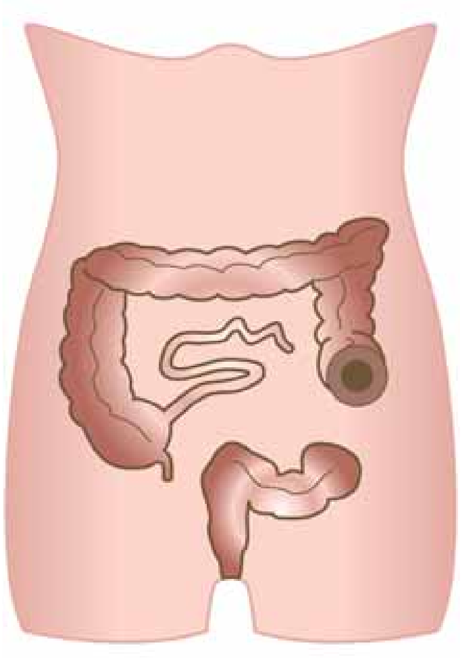
Sarah Squire x

The Rectal Stump

Yvette Perston
Clinical Nurse Specialist Functional Bowel Service
Queen Elizabeth Hospital Birmingham

What is it?

Surgeons will often leave a few inches of the back passage (rectum) behind when they operate on the bowel. This operation is called a *Hartmann's procedure*, and is often done as an emergency. The bowel is cut and one end is brought out onto the surface of the abdomen as a colostomy. The other end is the sewn or stapled closed and the anus is left intact. This blind-ended piece of redundant bowel is then called the rectal stump.



Hartmann's procedure

Why is it left?

This operation is performed because removal of the back passage, together with the anal canal, is a major operation which can leave a large wound which may takes some months to heal. Often the operation is initially done with the intention of reversing the colostomy. However, in reality this is not always possible either due to further treatment or because of the fitness of the person.

What can I expect?

The rectal stump will continue to live as it still has a blood supply. After the operation there will be a bloody discharge from the back passage because of blood left from the operation. Usually this produces a feeling of urge so that this can be passed into the toilet. However, this feeling is not always present and so leakages may occur. With time the discharge becomes mucus only and again this can be difficult for the sphincter muscles to control. The longer the length of the remaining section of your bowel, the more likely you are to experience rectal discharge.

As the entire bowel produces mucus to lubricate itself this will continue to occur and so an urge to empty the back passage will be felt occasionally. Most people can control this and wait to empty the back passage when it is convenient. Some people will get what looks like faeces from the back passage – this is because a percentage of what is passed is made up of dead cells shed from the inside of the bowel and not just food that has been eaten. Sometimes the urge is not present due to sensation in the back passage being lost following surgery; this may result in mucus just leaking out without warning. This may then cause some soreness to the skin around the back passage. There are many barrier creams available on prescription which can help with this. It is best to consult your stoma care nurse or doctor as to which one may be suitable. Wearing a small panty liner will also help by absorbing the moisture and so preventing chaffing of the skin.

Discharge – what's normal?

Most people get clear mucus or firm lumps. Although this can be smelly it does not mean that there is an infection. The smell is mainly produced due to the bacteria which live in everyone's bowel and is entirely normal. Most people get the sensation that there is something in the back passage and are able to pass it into the toilet. Some people get a permanent feeling that something is in the back passage (tenesmus) which can be very uncomfortable. The best way to relieve the feeling is to sit on the toilet and gently bear down as if you want to open your bowels. This will often expel any mucus. Some people will get the occasional episode of wind which is passed. Again this is normal and probably due to bacterial activity.

Why do I get it?

It is part of the body's natural function. There are cells in the bowel which produce mucus to help lubrication and they continue to do this even though there are no faeces passing through. A proportion of what is passed in stool is made up of shed cells from the lining of the bowel and these will continue to be produced.

As the bowel is very efficient at absorbing water from the stool it also absorbs water from the mucus. This can result in a very sticky discharge which can become solid lumps which are hard and painful to pass (this is called inspissated mucus).

When should I worry?

If the discharge becomes more copious and blood stained then it should be checked by a healthcare professional. This may be because a condition called disuse or diversion colitis may have developed. This is a specific form of colitis which can develop when there is no stool going through that piece of bowel. It is diagnosed by endoscopy and biopsy. The treatment for disuse colitis can be steroid suppositories or enemas or short chain fatty acid enemas. These should only be used under the guidance of a healthcare professional and after an endoscopy has been performed. The ultimate solution to disuse colitis is for the colostomy to be reversed and the rectal stump to have faeces going through it again. However, this is not always possible depending on the reason for the colostomy or the fitness of the person.

What can I do about it?

If the discharge is sparse and not very frequent and it can be controlled by the anal sphincter muscles then just going to the toilet when the urge is present will allow it to be passed. If the discharge is more frequent, hard to pass and/or the muscles are unable to hold it there are various ways of dealing with it.

Suppositories such as glycerine can be used on a regular basis to clear the back passage of a build up of mucus. These work by irritating the lining of the bowel and so clear the back passage. After insertion they usually work within 10-15 minutes. They are available on prescription or can be bought over the counter. They are very safe and can be used long term.

If the mucus is quite sticky and difficult to pass, small enemas such as Microlax can be used. The enema liquid inside the back passage lubricates and softens the mucus. This helps to remove the plug and prevent straining. Again they take 10-15 minutes to work and are safe to be used on a regular basis. They are available on prescription and should only be used on the advice of a healthcare professional.

Qufora Mini Used by kind permission of MacGregor Healthcare Ltd

Device for washing out the rectal stump

If neither of these interventions helps, the rectal stump can be washed out using a device which is available on prescription. There are two devices currently available on the market – the MacGregor Healthcare Qufora mini and the Oakmed Aquaflush compact system. They both enable the instillation of up to 90mls of warm water into the back passage. This is done whilst sitting on the toilet and enables the rectal stump to be washed out, thus preventing the build up of mucus. **They should only be used on the advice of a healthcare professional** and need instruction in how to use them.

All of these methods can be used on a regular basis to prevent the build up of mucus. The frequency of use depends on the individual and the amount and type of mucus produced.

What if these don't work?

For most people one or a combination of the above treatments is successful. However, sometimes they don't work. The definitive solution is to have the rectum removed. This would mean having the back passage sewn up. The advantage of this is that having no rectum means that there is nowhere for the mucus to form, and so the discharge would stop.

However, this is a major undertaking and is not possible in all cases. In some cases the wound takes a long time to heal and can be very painful. Also very occasionally people still feel as if they need to pass something from the rectum which is no longer there. Another risk is that the operation can cause damage to the nerves in the pelvis which may cause problems with sexual and bladder function. It is important to discuss the risks and benefits of this operation with the surgeon before deciding to proceed.

Conclusion

Many people with a colostomy have a rectal stump left after surgery. This can cause a variety of problems which extend from minor annoyances to major disruption to the quality of life. There are various solutions available and if this is a problem to you it should be discussed with your stoma nurse or your surgeon as to which may be suitable. Ultimately most of the problems can be eased or eliminated with carefully tailored treatments.

Yvette Perston

Gamgee Tissue

This is dressing made by Robinson Healthcare, Chesterfield and is also available from Fittleworth (code 26290T) Tel: **0800 378 846**.

It has been designed as a primary wound dressing for horses and designed for wounds that require additional dressing absorbency, and to give cushioned protection.

In comes in 500g rolls of about 50cm wide; you cut of the size that best works for you.

Because of its qualities as a dressing it is also ideal for when discharge is a problem and is used by a number of ostomates already.

Dear Nurse

**Julie Rust RGN. Dip, N. MSc.
Clinical Nurse Specialist
Stoma Care
University Hospital
of North Staffordshire**

Q: *I have a parastomal hernia which I developed not long after my stoma was created. However, I have also recently been told that I have an incisional hernia. Is this a different name for the same thing or is it a different hernia altogether?*

Also my stoma seems to change in size and shape and I have to re-do my template for cutting the pouches fairly often. Is this normal?

A: A parastomal hernia occurs around a stoma (para meaning around) whilst an incisional hernia occurs at any incision site (surgical wound). Both can occur at any time and are basically the same, being a weakness in the muscle but at different sites. An abdominal support may be beneficial to prevent them getting worse but this will not cure them; it is a support only. For a cure, surgery would be required and the possibility of this needs to be discussed with your surgeon. Whether he is willing to operate will depend on the level of problem the hernias are causing you and the surgical risk if you have any other medical problems.

Your stoma may be changing in size and shape because of the hernia around the stoma itself and this is quite common.

Q: *Before my operation I used to go to the tanning beds to get a bit of colour before my holiday. Can I still do that now I have a stoma?*

A: Obviously there are risks associated with any use of tanning beds and the added problem of having a stoma appliance can make this more difficult. Stomas and the adhesives can be susceptible to the extreme heat so caution should be used. If you decide to use a sun bed it may be beneficial to cover the stoma and pouch with an extra cover. Maybe using a self-tanning cream or a spray-on tan would be a better option.

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 CA are passed to Julie Rust RGN. Dip, N. MSc. CNS Stoma Care to review and answer. Answers are published in the next issue of Tidings.

Q: *I had a stoma after surgery last year. I decided I was ready to go abroad. I read all the advice both on line and in Tidings and took extra supplies as suggested. I normally use a two piece. The temperatures were extremely hot and the problem I had was that my base-plate started disintegrating in the heat. I did try using a one piece but the backing on this also started to disintegrate. Is this normal in temperatures over 35 degrees?*

A: Heat will have an effect on the adhesive and can therefore cause a problem. However, many ostomates go abroad without any problems but do sometimes find they need to change their pouches more frequently due to adhesion problems. Their skin may sweat more and cause the adhesive to lift. The use of an ostomy skin preparation i.e. a barrier wipe or spray may help in this situation.

Q: *My friend has an ileostomy due to Crohn's disease and she takes nutritional supplements and vitamin tablets. I had a Hartmann's procedure to form a colostomy, which the surgeon says he may be able to reverse. I find I can eat most foods without problem, only need to avoid sweetcorn because it passes straight through without being digested, and baked beans because they give me wind. Should I be taking nutritional supplements too?*

A: With a colostomy you are able to eat a normal, healthy and nutritious diet and therefore should not require food supplements or extra vitamins. I would advise you to continue on your normal dietary regime, only avoiding foods which you have identified as causing specific problems for you. Your friend has an ileostomy and therefore does have more dietary restrictions than you and may have been advised to take the supplements due to her surgery or to her Crohn's disease.

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

Colostomy Association Purple Iris Stoma Care Award

for outstanding stoma care and exemplary service to patients, families and carers within a Stoma Care Department or Community setting

Last year we launched our **Purple Iris** award for outstanding stoma care and exemplary service within a stoma care department or community setting.

Following the receipt of several nominations, the beautiful award was presented to the stoma care team of **St Mary's Hospital** from the Isle of Wight at our Open Day in Reading in July 2013 in recognition of their commitment to patients, families and carers.

This two yearly award is now open to nominations again so if you feel your stoma care team have contributed beyond the nursing remit to your care or that of a family member please complete the form below and return it to us by **15 January 2015.**

Perhaps your stoma care team have:

- **Been exceptionally caring and empathetic.**
- **Worked with other agencies to provide excellent patient care on a variety of issues.**
- **Used innovative ideas to deliver outstanding patient support to meet your needs.**

A representative from the winning stoma care department will be invited to attend our celebratory **10th Anniversary Gala Dinner** on Saturday 11 July 2015 in Reading when an official presentation will be made by our President.

We look forward to hearing all about the wonderful work being carried out by stoma care teams across the UK. Every nomination will be carefully considered and feedback will be passed on to them all as a welcome boost in recognition of their invaluable efforts.

––––––––––– Purple Iris Stoma Care Award – Nomination Form –––––––––––

Your details

First Name: ______________________ **Surname:** ______________________

Address: ____

______________________ **Post code:** ______________________

Telephone Number: ______________________ **Email:** ______________________

Nomination details

Name of team/department: ____

Name of hospital/community setting: ____

Reasons for nomination: ____

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

____

Additional Information

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

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

Signed: ______________________ **Name:** ______________________ **Date:** ______________

Please return this nomination form to: **Sue Hale, General Manager, Colostomy Association, Enterprise House,**
95 London Street, Reading, RG1 4QA by **15 January 2015.**

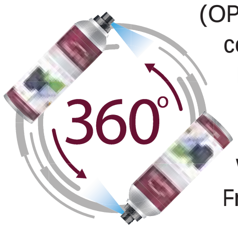
Update on stoma care products and services

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.**

OstoMART
Limited

OstoMART Ltd is pleased to announce the launch of 3 NEW Spray additions and a NEW Wipe addition to the OstoPEEL Medical Adhesive Remover range.

OstoPEEL Medical Adhesive Remover Spray is now available in Mint (OPM50), Apple (OPA50) and a No Fragrance (OPN50) Spray option to complement the existing Blackberry (OPB50) fragrance version and also in a Box of 30 Wipes with Blackberry Fragrance (OPBW30) - making the changing of stoma appliances and removal of stubborn adhesive residue easy and pleasant.



The OstoPEEL Sprays are a non-sting, propellant free, medical adhesive remover which uses bag-in-can technology. Benefits to you include - 360 degree dispensing (it can be sprayed at all angles), 100% product usage each time, does not spray cold on the skin and offers a '2 in 1' product meaning it eliminates odour as it removes the pouch.

OstoPEEL Sprays are over 41% cheaper than the market leading brand and no like for like prescription medical adhesive remover spray is cheaper than ours.

OstoPEEL is available to order now on prescription in a 50ml Spray or in a Box of 30 Wipes.

For further information please call Freephone **0800 220 300**,

email **enquiries@ostomart.co.uk**

or visit **www.ostomart.co.uk**

ESTEEM® + MOULDABLE

ConvaTec is proud to announce the launch of the new and unique **Esteem + Mouldable**.

The innovative pouch combines the ease and convenience of a one-piece pouch with the proven skin protection of ConvaTec Mouldable Technology™.

Research shows that the incidence of skin complications on ostomates is around 50% but not all of them report discomfort to their healthcare professional, but skin discomfort shouldn't be the norm!

Complications can occur due to changes in stoma size and shape, due to peristalsis or during the first weeks after surgery when the stoma is settling down. ConvaTec Mouldable Technology™ adhesives create a custom seal that 'rebounds back' to fit any stoma size and shape (with no scissors or templates required) and swell upward to enhance the seal.

The result is an incredibly secure, snug fit that moves with and responds to the stoma, as it changes after surgery and day by day.

CA News from the Office

The admin team continue to be very busy dealing with day to day enquiries, while also trying to raise public awareness and undertake campaigns. A brief update follows on general activities:

Prisons Campaign

Following on from contact made with the **Colostomy Association** this summer through *Time Inside*, Duncan Wells, **Colostomy Association** Trustee, is in the process of writing to every prison in the UK offering our support to inmates.

It is hoped that all 121 HM Prisons will be open to offering information about the support we can provide to its serving ostomates.

Toilet Cubicle Hooks Campaign

We recently wrote to every train company in Britain asking them to ensure each toilet cubicle had a door hook.

Some of the responses that have come in so far have been promising and are along these lines: "I can certainly appreciate the need for hooks in the toilets at our stations and agree these would be benefit for people, especially ostomates travelling with us. I have ensured that your comments are logged for the relevant management teams to view and take under consideration for future station changes.

"We're always looking for ways of improving our service and into ways we can make our passengers journeys more pleasant. Whilst I cannot guarantee that these improvements will be made a priority, please be assured that we will certainly look into this and see if we are able to accommodate your request."

If you know of a location where toilet cubicle door hooks do not exist, please let us know so that we can contact the organisation(s) concerned. It could make a big difference to thousands of ostomates.

Thanks so much!

Joint Campaign

Through the *Patients, Industry and Professionals Forum* supported by the British Healthcare Trades Association we have joined forces with the Urostomy Association and the Ileostomy Association to campaign for the rights of ostomates to ensure people continue to have a choice for suitable stoma care products to allow them to live comfortably and confidently.

This is becoming a threat across the country as Clinical Commissioning Groups (CCGs) try to reduce their NHS budgets. Jointly, we have produced a set of stoma product guidelines for GPs, nurses and CCGs to combat the increasing battle ostomates are facing as GPs try to reduce their spending against ever tighter budgets.

A "kit" is available from the **Colostomy Association** for those who are being challenged over their essential stoma supplies by GPs, keen to reduce their budgets.

Rapidcare

Rapidcare have kindly offered to make a one-off £15 payment for people who already receive stoma products through them, but who have joined the **Colostomy Association** as a result of receiving the tri-charity leaflet which was distributed by stoma industry suppliers to all their customers.

It's Rapidcare's way of encouraging their existing customers (who are not already **Colostomy Association** supporters) to join us. It should not be seen as a 'bribe' to attract new customers – they are simply paying a financial contribution towards our overheads on their existing customers' behalf.

So far, several supporters have benefited from this scheme which is wonderful. A big thank you goes to Rapidcare for signposting to the **Colostomy Association** and for their financial support.

Do you care for somebody with Dementia or Alzheimer's disease?

Dementia UK describe the symptoms of dementia as increased forgetfulness, loosing items regularly, poor short term memory, confusion, mood swings, problems with communicating, poor concentration, getting lost in seemingly familiar places and repeating oneself regularly.

So it follows that if an ostomate develops dementia this can be a challenge. However, if a person who already has dementia requires surgery to form a stoma, this can be even more problematic as they may be unable to learn or remember the techniques to cope with a stoma.

At head office we receive a number of calls from carers who look after ostomates who have dementia and we feel it might be helpful to put these carers in touch with each other so they can share experiences, problems and solutions and provide each other will mutual support.

If you feel it might be helpful to communicate by phone, email or Facebook with somebody else caring for an ostomate with dementia, contact the admin team and we will try to put you in touch with others in a similar situation. Additionally, if you know anyone who felt able to contribute to a new information sheet on how to support ostomates living with this disease, please put them in touch with the office.

How to contact Tidings
By letter write to:

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

By telephone:
0118 918 0500

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

By now most people will have heard of a bucket list as a way of achieving their ambitions and living life to the full, so we thought it might be a nice idea to suggest a few pointers including some worthwhile practical ideas.

1. Travel aspirations, eg seeing the Pyramids or visiting Machu Picchu.
2. Catching up with long lost relatives or friends.
3. Volunteering for a local good cause.
4. Taking a bowel cancer screening test.
5. Having a prostate gland test or mammogram.
6. Checking your cholesterol levels.
7. Making a Will.

There is no right way or wrong way of making a bucket list but it is important in life to try to do the things that really matter. We only tend to have regrets about things we've not tried to achieve. Writing down a wish list can be quite cathartic and it'll give you a great sense of achievement when an item can be ticked off. Why not start making your bucket list today? Here are a few tips:

- Write it down (and use as a regular reminder)
- Have a minimum of 5 items (it can always be extended to 10 later)
- Make the items personal to you and specific (so that you don't lose heart)
- Include things that will make you feel good (such as volunteering)
- Keep your goals realistic but achievable

So, what's stopping you? This exercise could bring a lot of enjoyment and certainty to your life. The fun items are what living life should be all about!

On a more serious note, taking regular bowel cancer screening tests are vital to your longer term wellbeing. Even if you've had stoma surgery, it is important to continue these tests.

While this is often a taboo topic, it's one that everyone should seriously consider. Why not make your Will soon and think about the impact of a potential legacy to charity too?

This edition of *Tidings* contains a reference to companies who are offering their services free in November to those aged over 55 for Free Will Month… Why not take advantage of this free (basic) Will writing service – for the benefit of your loved ones. They will thank you for it, when you've gone and your legacy will perpetuate the good work of your nominated charity!

Don't forget our Recycling Appeal

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

Freepost envelopes are available or collections can be organised, simply visit:

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

Readers' writes

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

Rosemary Brierley

Dear Editor

For many years I suffered from diverticulitis and then ulcerative colitis. I gave up all foods which contained small seeds but otherwise had no problem until I was 73. Two years ago the steroids stopped working and I was taken by my wife to hospital with severe rectal blood loss. I was operated on three days later.

The stoma nurse came to visit me on the ward a couple of days after the operation and talked to me about the stoma and showed me how to deal with it. I have a drainable pouch. I knew nothing about such a thing before I went into hospital. I had various other problems, such as urine infections, immediately after the operation, but within a few weeks all was set up.

I do not take any drugs other than Warfarin. The major lesson I learned was to ensure that all pills I take are not coated as the coating prevents the drug being absorbed and they go straight into the pouch.

I had a proctectomy (removal of the rectum) twelve months after the ileostomy.

Everything works, I eat less, I empty my pouch twice per day. I have no skin problems. I do use a Sash belt occasionally. I now have to wear braces as the stoma is on the belt line but I have found braces with Scottish flags on. Guess my Nationality!.

I find a stoma bag irritating but it has kept me alive and I am grateful for that.

Regards
J.D.

Dear Editor

I decided to have a hernia 'op' a year ago because my hernia was getting rather uncomfortable and heavy. I was never very good at wearing a support belt as I found them tight and a bit hot when playing golf in hot weather. When I said to my surgeon that perhaps I had brought this hernia on myself by lifting heavy things such as a golf bag, golf trolley and shopping, he said, 'Not necessarily. It may have happened anyway, so who knows.'

I now wear a support garment when doing anything active because I am paranoid about a hernia returning as the operation was the worst one I have experienced.

It took two and a half hours, and six weeks to recover with a lot of post-op pain.

I did ask my surgeon what the odds were of a hernia returning and he said about 5 to 10 percent, but how does he know when I am sure a lot of people would never go back and have that operation again - they would rather live with it!

Having said all that I am now pleased that I took the decision to have the operation as my stomach is reasonably flat and more comfortable.

I hope this letter is helpful to anybody faced with the decision of the dreaded hernia 'op'!

Regards
J.H.

It is thought that wearing a stoma support garment after surgery can reduce the risk of developing a parastomal hernia. Ostomates are advised to discuss this with their stoma nurse who will be able to provide advice on which type of garment will be most suitable.

Dear Editor

You asked for comments on disposal of stoma products. I have had a colostomy for 12 years and my very good nurses said don't make a fuss. Make sure they are well sealed and put them in with your household rubbish. I have never had any trouble when away from home. I double/triple wrap in carrier bags from shops etc. and leave them in waste bin in bathroom. Never had any complaint.

While I am in a writing mood a note about supplies: I started with a one piece and repeat prescriptions every two months. After a while I changed to a two piece

Readers' writes

because my skin was getting sore and the bag often came off.

Because items are packed in assorted numbers i.e. bags 30, base plates 5, adhesive remover wipes 30, barrier wipes 50 it was hard to order and reception at my doctor's surgery insisted I had the same order every two months.

I got fed up with having too many adhesive remover wipes and always being low on base plates. When it was time for my prescription review I took my travel bag and some boxes with me. I explained to the doctor the trouble I had reordering and showed him a bag change. I explained it was very costly and time wasting to order every two months.

After a while it was agreed that I order what I want in the quantities I need every three or four months. I can now order early for Christmas and holidays. I'm not into computers very much so I write what I need on a piece of paper deliver it by hand to the surgery and collect the prescription next day and post it off to my supplier.

D.E.F.

Dear Editor

Re: Spring issue 2014 Reader's letters

In response to A.B.'s problems when ordering their colostomy supplies I decided to take matters in to my own hands.

I too had problems when my local CCG brought in the new regulations. I could not rely on my supply company to order a prescription from my doctor in plenty of time and the doctor's practice seemed to have no urgency in posting the prescription to the supply company.

I now contact my doctor's practice to obtain a prescription, when I have it in my hand two days later I telephone my supply company and order my colostomy supplies. I often give them the prescription number and we arrange a delivery date, usually within a couple of days. The supply company now has it on record that I will supply the prescription by first class post in a prepaid envelope within two days and they are happy to release the goods.

So far the system has worked well and I feel that removing two uncontrollable factors from the equation has served to give me the peace of mind that the original system used to give.

Yours sincerely
K.M.

Thank you to all our readers who wrote to tell us how the length of time between ordering and receiving stoma supplies is increasing (in some cases when the delivery company requests the prescription from the doctor, it can be as long as three weeks). We do not have space to print all these letters in this issue, instead we have included an article based on our factsheet, Obtaining Prescription Supplies *on page 17.*

Dear Editor

I have had a colostomy for almost four years now, due to complications with Crohn's disease resulting in a non-functioning rectum and incontinence from time to time. Previous to this, I had to have a third of the large bowel removed due to Crohn's. Then I was offered another operation to improve the function of the rectum but chose to have a colostomy instead. I have never regretted this as it is so much better than the agony I had before. I have read very few comments from people who have had a colostomy due to these problems.

The stoma nurses never informed me about irrigation. I was told about it by another ostomate at a meeting of suppliers arranged by the hospital. After instruction by the nurse, I have never looked back. My skin is so much healthier and the worry is much less. I still have to be careful though, and if I am going away, I use a drainable bag and an extra adhesive strip around the outside. This works very well.

I have found the magazine very useful and am happy to support you,

Yours sincerely
S.H.

Dear Editor

I would endorse many of the comments made by fellow colostomate A.R. (Spring 2014 Issue) With the knowledge gained through such letters and articles within Tidings, my life at 75 years of age has become more of an adventure than just a life.

The Welland flushable pouches renewed my confidence and pleasure in flying to USA this year (Europe later this year). Overnight visits to family and friends, and longer day trips are now planned with delightful anticipation. An adventure can bring the odd hiccough but bring it on!

Heartfelt thanks to everyone providing the solutions.

F.H.

Dear Editor

Apropos of the article about disposing of appliances, can you advise about the disposal of the cover of flushable bags? They are supposed to be recyclable but the local authority says to put them in landfill. Do you know about how to recycle them?

Thanks
Peggy Thomas

Rory Smith, Director of Research and Development, at Welland Medical, who invented the flushable pouch, sent this reply:

Recycling of plastics seems to be handled haphazardly across the country. The more advanced local authorities seem to at least encourage householders to collect plastics together. Some plastic packaging now has an identifier for the type of plastic used, which consists of a triangle with a number inside and initials beneath. However, I don't know of any local authorities yet asking householders to segregate their plastic waste into individual plastic types.

The outer cover of the flushable bag basically consists of a mixture of different plastic materials making up the fabric and film ie Polyester (PET), Poly Vinyl Di-

Readers' writes

Chloride (PVDC), Ethyl Vinyl Acetate (EVA) and Poly Amide (Nylon, PA).

On this basis we would expect the outer cover to be recycled with other mixed plastic waste (Category 7) or with other unsegregated plastic waste.

The one caveat is that the cover should be unsoiled, and I wonder if this is why the local authority, in ignorance, is advising landfill, which as we all know is not ideal.

If the flushable liner contains the waste as it is designed to do, then my view is that the outer cover should be sufficiently clean to be placed in the appropriate plastic recycling bin (the liner containing the waste is flushed away in the toilet).

Hi

I can tell your correspondent to *Dear Nurse* (*Tidings*, Issue 34, page 47) exactly what to do with the filter covers ("stickers") from their boxes of pouches - send them to me, **PLEASE!**

My mother has recently discovered that using filter covers on her pouches solves her pancaking problem and the related problem of pouches pushing off the skin and poo falling on the carpet when she stands up; the covers break the vacuum in the pouch, allowing the waste to enter. As mum uses a drainable pouch, she does not receive filter covers and the delivery company were only able to supply a dozen or so. She currently cuts up sticky labels to use but I'm sure custom made filters would work even better.

I am happy for you to publish my email address for people to contact me:
lyndavwilliams@hotmail.com

Many thanks.
Lynda Williams

Dear Editor

I spent Christmas 1998 in Leicester Royal Infirmary having had a colostomy on December 21st. I had rectal cancer which came as a great shock to me and my wife. I had several mishaps in the early months and was very nervous when away from home, especially in other people's houses. I was also conscious of odour when sitting down.

Over the years I have developed a hernia and need to wear a support belt which is not very practical with a normal pouch because I found it could cause pancaking and leakage behind the flange. I had often thought about irrigation and wondered if it would be suitable for me. I had an appointment with my stoma care nurse at the beginning of this year and she kindly arranged for me to see my surgeon. After the all clear was given I started irrigation almost immediately. The stoma nurse came two mornings to instruct me and then again to see how I was getting on. I have never looked back and wished I had done this, years ago.

I irrigate between 8 o'clock and 9 o'clock in the evening. That is my quiet hour when I plan my D.I.Y. or have a shave as irrigating can be quite boring. My wife has the television programmes of her choice downstairs.

It is now six months on and I have just returned from a very peaceful holiday in Norfolk – no problem at all. I feel much better and at 91 I still do my garden and any D.I.Y.

Thanking you

Ted

Thank you for your letter, Ted. Although we are hearing from more and more ostomates who begin irrigating in later life, we think at 91 you must hold the record.

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.

Don't forget our Recycling Appeal

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

Freepost envelopes are available or collections can be organised.

Simply visit:

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

colostomy association

Open Day 2015
& Fashion Show
Colostomy Association celebrates 10 years

Date:	Saturday	11th July 2015	Time:	9:30am - 4:00pm
	Sunday	12th July 2015		10:00am - 1:00pm

2005-2015

ConvaTec

MODELS WANTED

- Would you like to walk up the cat walk?
- Do you have a secret hankering to be a model?
- Are you interested in modelling clothes from the High Street chains at our fashion show on the morning of Sunday 12 July?
- No modelling experience is necessary – and you don't have to be young, thin or beautiful!
- We need both male and female ostomates of all ages, shapes and sizes to strut their stuff for us at this celebratory event so please get in touch if you'd like to be involved.
- It will be a wonderful event and you'll have the opportunity to walk along the catwalk in front of family and friends in a variety of outfits!

The fashion show will aim to demonstrate ideas of how to look good for different occasions and an image consultant will be deciding which clothes are worn by whom. Sounds like fun!

The fashion show forms part of our special 2015 10th Anniversary event and is being kindly sponsored by ConvaTec, which is much appreciated.

However, we're sorry we're unable to cover your travel costs but hopefully you'll feel able to join us for the morning. Or even come along to the open day on the Saturday beforehand and join the celebratory fundraising Gala Dinner on the Saturday evening too!

If you're not keen to be a model, put the date in your diary as we'd love to see you there anyway!

(More information on tickets will follow in the January 2015 edition of Tidings so watch this space.)

We hope to hear from you soon – Real people modeling the latest fashions

Contact: **Sue Hale** Tel: **0118 939 1537** or e-mail: **cass@colostomyassociation.org.uk**

NO SIZE ZERO — NO AIRBRUSH – JUST REAL PEOPLE

The breakaway Foundation

The MACE (or ACE) PROCEDURE

The letters forming the word **MACE** stand for **M**alone **A**ntegrade **C**olonic **E**nema.
The operation is also known as the **ACE** procedure.

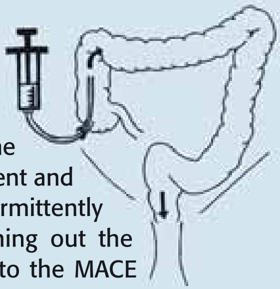
A MACE is formed as an alternative treatment for bowel management after initial conservative treatment has been ineffective for long term soiling/faecal incontinence or severe constipation. A MACE is also used in children who have a physical malformation of their rectum and/or anus or nerve damage to their large bowel, which causes soiling/faecal incontinence or severe constipation.

The MACE is formed using the appendix. It is brought out onto the abdominal wall to make a very small stoma. The appendix then forms a channel into the bowel which can then be catheterised to give a stimulant and water solution to wash the bowel out.

The MACE, in the majority of children, will not leak faeces out onto the abdomen as it is formed in such a way as to make a valve mechanism which will stop faeces/fluid coming back out.

If there is no appendix present (due to previous removal or the appendix is not a good size), a tube is formed using part of the bowel called the caecum or the small bowel.

Initially while in theatre a catheter will be inserted through the stoma into the bowel. This is then connected up to a tube and a bag containing a water and stimulant solution. The bowel is flushed through with this, and poo is passed through the anus into the toilet.



When the surgery has settled down, the catheter can be removed and the parent and child can be taught how to intermittently catheterise the MACE prior to washing out the bowel. A *stopper* is then inserted into the MACE hole to keep it open until the next washout is due.

Over the past year or so, there have been moves to introduce a different form of bowel treatment into centres specializing in bowel management in children. This is called *trans-anal irrigation*. A small tube is inserted into the anus and the descending colon is flushed with a large volume of water and the child then passes poo into the toilet. This method is often recommended initially so that the surgeon can see if a MACE would work for each individual child and family.

Rachel Wade
Children's Gastroenterology Specialist Nurse for Surgery
Children's Hospital, Leicester Royal infirmary

Lots of the Breakaway children have ACEs, a procedure that can radically change their life, giving them back continence and allowing them to live their life free from worry about soiling or constipation. In this article some of our families share their thoughts about having an ACE.

Sarah's Story

Since Sarah was born she has suffered from chronic constipation which has caused huge distress to our family. Having to give enemas and force-feed her medication was so hard for us. The doctors always told us she would grow out of it so we waited for each milestone, nursery, primary school, but still it persisted. After researching a lot we discovered the Breakaway Foundation and found out about the ACE. We were wary of making any big decisions but after seeing all the other children proudly showing off their ACEs at a Breakaway event, we made the decision to go ahead with the surgery. Surgery went well and Sarah was soon improving. Knowing that our Breakaway family were there to guide us when we stumbled made life a lot easier for us all.

Zak's Story

When Zak was born they discovered that he had imperforate anus. Within 12 hours of birth he had surgery to form a colostomy. Over the next nine months he had several surgeries to create a new bottom, and correct other abnormalities. Physically they did make him a new bottom, but a further six months down the line we knew that it wasn't working so well. He was soiling pretty much constantly - 30+ nappy changed a day - and in agony from excruciating nappy rash that left him with raw sores on his bottom. We were told that the faecal incontinence was unlikely to change.

We went on like this until he was three, when a new surgeon joined Zak's team and he talked to us for the first time about performing an ACE. He had the procedure in 2012 and it took a lot of getting used to. Now we're settled into it, and we have to give Zak an enema every evening, which takes between one and a half and two hours. We battled through this journey alone, but about a year ago I stumbled across Breakaway. For the first time ever we had people to talk to who knew what we had experienced and continue to battle with, people who could lend an ear to listen, a shoulder to cry on.

More information about Breakaway Foundation.

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

Write to us or send a donation to:
Breakaway Foundation
PO BOX 7982
Swadlincote
DE11 1FB

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

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

- 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)
  (The United Ostomy Association in 1982 established the Gay and Lesbian Concerns Committee, now called Gay and Lesbian Ostomates (GLO) Network.)
  Web: www.glo-uoaa.org

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

Stoma Care Patient Open Day event dates

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

Listings are updated throughout year.

If you are not online

contact CA on:

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

Note: The Colostomy Association full contact details can be found on Page 7.

Apply for a **Guaranteed Place in Virgin London Marathon 2015**

The Colostomy Association has been successful in winning a charity place in the Virgin London Marathon 2015 on 26th April 2015. We would like to offer this place to one of our readers or their family and friends.

If you are the lucky applicant, we promise to support and encourage you all the way to the finish line! We will also provide you with a running vest and put articles on our website and *Tidings* letting people know how you are getting on with training and how they can sponsor you to help you achieve your fundraising target.

Applications should be made in writing using the form below and returned to:

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

All entries must be received by **30th November 2014**

Apply for a chance to win a Guaranteed Place in **Virgin London Marathon 2015.**

Confirmation of single application

☐ I understand that I am applying for one place for use by myself and nobody else.

Why have you chosen to take part in this event? ______________________________

______________________________ CONTINUE ON SEPARATE SHEET IF NECESSARY

Registration fee acceptance

☐ I understand that if my application is successful I will be required to **pay a registration fee of £75** to secure my place.

Pledge acceptance

☐ I understand that if I am successful in gaining the **Colostomy Association** place I am pledging to raise a minimum sponsorship amount of **£1,500** excluding Gift Aid, **by Friday 5 June, 2015.**

Virgin Money Giving fundraising page

☐ I understand that if I am successful in gaining the **Colostomy Association** place I will be required to: set up an online fundraising page with Virgin Money Giving.

Holding fundraising events are the best way to raise significant amounts of money towards your total. Please describe what events you plan to hold, who you would invite to them, and how much you expect them to raise?

____

______________________________ CONTINUE ON SEPARATE SHEET IF NECESSARY

Traditional fundraising methods using sponsorship forms, collection tins and raffles remain an ever popular and successful way of fundraising. Please explain in detail how you would use such forms of fundraising to reach your target?

____

______________________________ CONTINUE ON SEPARATE SHEET IF NECESSARY

For the running vest what is your chest size (and bust for women)? __________ What is your date of birth? __________

Minimum age

☐ I confirm that I will be eighteen years or older on race day.

Permission to record

☐ I agree to photography or video/audio recordings of me being taken for use in **Colostomy Association** publications and the media, to promote the work of the **Colostomy Association.**

What is your motivation for wanting to support the **Colostomy Association?**

______________________________ CONTINUE ON SEPARATE SHEET IF NECESSARY

Name: ____________________ Tel/Mobile Number: ____________________

Address: ______________________________

____________________ Post code: ____________________

Email address: ____________________ Signature: ____________________

Marketplace

advertise your events • messages • services here

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

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

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Somerset, TA5 1ZA

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www.iMEDicare.co.uk

Stevenage Ostomistics

– Open Day –

Saturday 29 November 2014

The Oval Community Centre,
Vardon Road, Stevenage SG1 5RD
10:30am to 1:00pm

For more information call:

Judy Colston: 01438 354 018

A variety of manufacturers, Refreshments available and Ample free parking

PLEASE MENTION TIDINGS WHEN CALLING.

Colorectal Health & Wellbeing Event
The Breast and Endocrine Unit, Ulster Hospital
Oct 21st 2014 – 6:00pm
Sandra Whitla:
sandra.whitla@setrust.hscni.net

Forth Valley Royal Hospital Stoma Care Open Day
The Park Hotel, Falkirk
Oct 22nd 2014
Lesley Newlands: 01324 566 299

Salts Healthcare
Holiday Inn, Stewartfield Way, G74 5LA
Oct 23rd 2014 – 11:00am–2:00pm
Salts Healthcare: trevor.donald@salts.co.uk

Macclesfield Hospital SCD Open Day
Macclesfield Masonic Hall
Oct 25th 2014
Deborah Eingleton: 01628 661 598

Kingsmill Stoma Care Department Open Day
Holy Trinity Church Hall, Boundary Road, Newark, NG24 4AU
Oct 28th 2014 – 11:00am–2:00pm
Jane Cook, Stoma Care Department

Luton & Dunstable Hospital Stoma Care Open Evening
The Chiltern Hotel, Luton, LU4 9RS
Nov 25th 2014
Stoma Care Team

PLEASE MENTION TIDINGS WHEN CALLING.

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PLEASE MENTION TIDINGS WHEN CALLING.

Contact –
editor@colostomyassociation.org.uk

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colostomy association

Thank you for your support

Regular donation

Your on going commitment means CA can plan its services with confidence safe in the knowledge that regular donations will be received. Help CA to reach out to more colostomates their families and carers to give support, reassurance and practical advice to those in need. With your help we really can and do make a difference - thank you!

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

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

My Details: Title: Name: Surname:

Address:

Postcode:

Telephone (home): Mobile:

Email:

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

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

To the Manager: (Bank or Building Society)

Bank Address: Postcode:

Name(s) of Account holder(s):

Account number: Sort code:

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

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

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

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

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

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

Name: (IN CAPITALS)

Signature: **Date:** / / 2014

giftaid it

Thank you for your gift

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

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

Signature: **Date:** / / 2014

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

Reason for your stoma: (Please tick) Ileostomy ☐

Year of operation: Urostomy ☐

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

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

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

Registered Charity No: 1113471

colostomy association

Thank you for your support

Single donation

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

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

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

My Details: Title: Name: Surname:

Address:

Postcode:

Telephone (home): Mobile:

Email:

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

Reason for your stoma: (Please tick) Ileostomy ☐

Year of operation: Urostomy ☐

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

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

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

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

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

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

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

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

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

giftaid it

Thank you for your gift

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

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

Signature: **Date:** / / 2014

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

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

Registered Charity No: 1113471

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.

Have you thought of joining a support group?

The chances are that apart from the contacts you may have made in hospital you have never met anyone with a colostomy, ileostomy or urostomy.

It was almost a year before I met another person with a stoma, after having received my colostomy because of an operation for cancer. Although I had the excellent support of my stoma care nurse and district nurse, neither thought of introducing me to someone who was 'further along the journey' than me.

I began to feel isolated as I had no-one to talk to about the way I felt and who could possibly understand just what I was going through while trying to come to terms with my colostomy. My husband was terrific in his love and support but I needed to meet other people who were in the same situation as myself.

Luckily for me I saw a coffee morning advertised and organised by the local stoma care nurse and went along to see if I could meet other stoma patients. From that moment on – I received good and sound advice, hints and tips and more important, friendship.

I stopped feeling isolated and it was wonderful to meet other people who were in the same situation as myself.

It was not long after that I was asked, by the local stoma care nurse, if I could start up a support group for people in the Bracknell area. The East Berkshire Ostomy Club (EBOC) for ostomates was established in 2005.

Support groups are run throughout the UK – some meet during the day, some in the evening, some at weekends. Some may meet every week, some every month, some every quarter but when they do meet it is to offer friendship and support. The *Tidings* magazine has a list of support groups, contact numbers and localities – use the information to ask about the group and its members.

EBOC meet every Monday afternoon, 2:00pm-4:00pm at the local community centre and I am thrilled that the Trustees of the centre provide the meeting room free plus give us a generous donation each year that allows us to hold an outing for the members. The meeting is free although we do hold raffles and run a book club at 20p per book to help funds. Other groups may have found other ways to fund their meetings, but you will always find a warm welcome by the members who know exactly how you feel.

EBOC, like many other support groups, is a non-medical group whose objective is to provide a social atmosphere where colostomates, ileostomate and urostomates and their partners/friends can meet and share experiences and problems.

I well remember a young woman visiting our meeting one Monday afternoon, declaring: "...her life was over now that she had received a colostomy". She felt that she could no longer work, or enjoy any of the kind of life she had experienced before her operation.

The members made her welcome, spoke to her, encouraged her and after two hours she left the meeting. We did not hear from her until some weeks later when I received a letter asking me to thank the members for their support, advice and encouragement. She had returned to work was looking forward to a full and busy lifestyle – because – if "we" could do it then so could she.

Go along to the support group in your area, meet the members who are people like yourself, who have been in a similar situation but now have the experience of living with their stomas.

Jackie Dudley

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

France
Stoma France
Contact – Adrian March: +33(0)494501136 or email: info@stoma.fr

Spain
Costa Brava
Contact – http://www.ostomyinspain.org/

A

Avon
Bristol Ostomy Self Support (BOSS)
Contact – Janet on 01934248114 or Rob on 0117 966 8021

Ayrshire
Ayrshire & Arran Stoma Support Group
Contact – Jim Krasewitz: 01292 220945

Stoma Care And Recovery (SCAR)
Contact – Maggie: 01294 271060/ 07817736147 maggie13@sky.com or Rhona: 01294 557478

B

Bedfordshire
Saturday Social Club
Contact – Karen Richards: 01234 792278

Berkshire
E.B.O.C (East Berkshire Ostomy Club)
Contact – Jackie Dudley: 01344 426652

W.B.O.C (West Berkshire Ostomy Club)
Contact – Jackie Dudley: 01344 426652

Buckinghamshire
Milton Keynes Stoma Association
Contact – Joanne Dickson 01908 318262

C

Cambridgeshire
Ostomistics
Contact – Alan Wright 01354653290 / 07836661102

Cheshire
Stockport Support Group
Contact – Angela Simpson: 01613209400 / 08006526667

Stoma Support Group
Contact – Catherine McIntosh: 01270666985

Warrington Ostomy Support Group
Contact – Jane Shaw: 01925 662103

Cleveland
Oops Group
Contact – Julie Morrisroe/Carol Younger: 01287 284113

Cornwall
Cornwall Bowel Cancer Support Group
Contact – Peter Yorke: 01726 821 280
E: quilpusha@gmail.com
U: www.cornwall-bowel-cancer-support-group.co.uk

Optimists
Contact – Sue Hatton: 01326 340058

Ostomist and Carers Support Group
Contact – Christine Davey: 01208 831471

County Antrim
Antrim Area Stoma Support Group
Contact – Chris Wright: 07720 717771

Colostomy Association Volunteers Northern Ireland
Contact – Chris Wright: 07720717771

Mater Hospital
Contact – Karen Boyd - Stoma Nurse: 02890741211 Ext 2329

Royal Victoria Hospital - Belfast
Contact – Sarah Haughey/Audrey Steele: 02890240503 Ext 3483

County Armagh
Craigavon Area Hospital
Contact – Mary Jo/Bernie: 02838612721

Daisy Hill Hospital Support Group
Contact – Bernie Trainor: 02830 835000 Ext 2222

County Down
North Down Stoma Support Group
Contact – Adrian Ewing on 07850741511

Ulster Hospital
Contact – Hazel/Martina: 02890550498

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

County Fermanagh
Erne Hospital
Contact – To be confirmed

County Mayo
Mayo Stoma Support
Contact – Marion Martyn: 094 902 1733

County Durham
Bishop Auckland Stoma Care Group
Contact – Betty: 01388 814535

Cumbria
Grange Cancer Support Drop in
Contact – Marie: 015395 33279

D

Derbyshire
Diverted Local Stoma Support Group
Contact – Diane Manning: 01283541311

Devon
Mid Devon Ostomy Support Group
Contact – Janice: 01363 776 417 or janicedianeparkyn@yahoo.com

Dorset
Colostomy Urostomy Pouch Ileostomy of Dorset (CUPID)
Contact – Beryl Andrews 01202 483303

Colostomy Urostomy Pouch Ileostomy of Dorset (CUPID)
Contact – Jenny Pipe: 01202740440

Colostomy, Urostomy, Pouch & Ileostomy of Dorset - CUPID (West Dorset)
Contact – Colin Clare - 01305 853238

E

East Midlands

Newhall Stoma Support Group
Contact – Diana Manning: 01283541311 or Helena: 07932331850

Essex

Connect
Contact – Lin Hart 01279 505273

Mid Essex Stoma Support Group
Contact – Paul Foulger: 01245 224374, Jeanette Johnson: 01376 511862

N.E.S.S (North Essex Stoma Support)
Contact – Secretary: Brian Waller: 01206 540449

Optimistic Ostomates
Contact – Carol Booth: 01702 385510 or Angela Taylor: 01702 385509

Redbridge Ostomists Club
Contact – Stoma Nurses - Chris/Lisa: 0208 9708321

South Essex Young Ostomy Group
Contact – Paul Gray: 01708 501268

STEPS
Contact – Jackie: 01268 451937

F

Fife

Fife Ostomy Support Group
Contact – Ishbel Barr: 01592 772200

G

Gloucestershire

Ladies Big Op Group
Contact – Gill Hopkins: 0300 4224 363. Please Note: For ladies with one or two permanent stomas

Guernsey

Guernsey Ostomates
Contact – Luci Deane 01481 236077 / lucideane58@gmail.com

H

Hampshire

Optimistics
Contact – CNS's Andie Coates & Amanda Broadbridge 01983 534009

Semi-Colon Club
Contact – Tony Crowson on 01983 559326 or CNS Helen Fulford 01983 534180

Solent Ostomates Support Group (New Forest Branch)
Contact – Carole Summer: 07527707069

Solent Ostomates Support Group (S.O.S.)
Contact – Carole Summer: 07527707069

Southampton Support Group
Contact – Carole Summer: 02380 446779

Wessex Urology Support Group
Contact – David Morris: 07910786978

Hertfordshire

Colonise
Contact – Anastasia 01727 760981

Hertford Stoma Support Group
Contact – Ralda: 01992 535311

Stevenage Ostomistics
Contact – Judy Colston: 01438354018/neilcolston@btinternet.com or Alfred: 01767316958

I

Isle of Man

Stoma Support Group
Contact – Carole Cringle stoma nurse: 01624 650212

K

Kent

Ashford Stoma Support Group
Contact – Ron Huckstep 07941 310681 : Margaret Webb 01233 628807

Atoms Support Group
Contact – Maria Culleton, SCN: 01227 769679 or 07827997424

Dover & District Stoma support
Contact – Maria Culleton SCN: 01227 769679

Dover Stoma Friends Group Support
Contact – Julie Bell: 07771345703 or Ros Marshall: 01304822696 or June Golding (Organiser): 01304822696

M.O.G.S (Medway Ostomy Group Support)
Contact – Helen Or Tracey: 07773605534

Royal Tunbridge Bowel Cancer Support Group
Contact – Bronwen Tetley CNS: 01892 526111 x 2287

Thanet Stoma Buddies Support Group
Contact – Phil (Secretary) 0184 3587 769

Used Stamps needed

Do you have any used stamps you can donate? People are refunded their postage in full as long as they mark the envelope for the "CA" when sent direct to this company (and use commemorative stamps as they become part of the fundraising).

Any stamps are taken but the commemorative stamps are the most valuable because they relate to special events. £10 per kilo is paid including the weight of the envelope.

Instructions to stamp donors:

- No more than 1cm of envelope left around each stamp (as per photo).
- Not trimmed too close so that the perforations are damaged.
- Use special commemorative stamps on the envelope when sending.

Please send your used stamps to:

'CA', 35 Wrecclesham Road,
Farnham, Surrey. GU9 8TY

L

Lanarkshire

G66 Support Group
Contact – Les Ireland 0141 7763866

Glasgow Stoma Support group
Contact – Chairperson: Maureen O'Donnell: 01236 436479

Leicester Royal Infirmary Colorectal Support group (Moving on)
Contact – Wilf Patterson (secretary): 01455 220344

North Manchester and Bury Stoma Support Group
Contact – Julie Meadows (SCN) 0161 720 2815 or 07841206910

Oldham Stoma Support
Contact – June Wilde: 0161 3125538

Tameside Ostomisticles
Contact – Paul Seavers on 0777 1359046

Trafford Bowel Care
Contact – Jackie Carey Secretary: 0161 7489659, Doreen: 0161 9627818, John: 0161 7484655

Leicestershire

Kirby Ostomy Support Group. Colostomy, Ileostomy and Urostomy in Leicestershire
Contact – Janet Cooper: 01162392844/ kosg2013@btinternet.com

Lincolnshire

Friends East Coast Support Group
Contact – Betty: 01205 724120, Sheila: 01205 364493

Grantham Support Group
Contact – Bobbie/Amanda: 01476 464822 or grantham.colorectal@ulh.nhs

March Group
Contact – Sharon Palmer: 07414828867 or sharonpalmer44sp@gmail.com

Sutton Bridge and Long Sutton Ostomy Group
Contact – 01406 351617

London

Bowel Cancer Newham
Contact – Scyana: 0208 5535366 scyana@tiscali.co.uk

ESSence (Ealing Stoma Support Group)
Contact – Marcella: 07825 186783

Homerton Hospital Bowel & Stoma Support Group
Contact – Angela Davy: 02085105318 or 02085107599

South Woodford Support Group
Contact – Nurse Christina and Lisa: 0208 5356563

St. Thomas' Hospital
Contact – CNS: 0207 1885918

Surrey & South London Bowel Cancer Support Group
Contact – Sue Berry: 01737 553134 or John Amos: 02086680796

Londonderry

Causeway Support Group
Contact – Mary Kane: 02870346264

M

Merseyside

I.C.U.P.S
Contact – SCN: 0151 6047399

Middlesex

Inside Out
Contact – Sarah Varma: 020 82354110 Bob (chairman): 0208 4284242

Semi-Colon Club
Contact – Pat Black or Kathryn Foskett on 01895 279391

Midlothian

GOSH (West Lothian)
Contact – Scott Pattison: 07502163644

Maggie's Edinburgh
Contact – Maggie: 0131 5373131

N

Newcastle

NHS Molineaux Walk In Centre
Contact – Lesley Brown: 0191 2826308

Royal Victoria Infirmary Support Group
Contact – Gordon Weatherburn: 0191 2341109

Norfolk

Kings Lynn Ostomy Friendship Support Group
Contact – For more info please call 01553 691370 / 768271 / 775698

Stars
Contact – Anne Browne: 01603 661751

Northumberland

Berwick Ostomy Support Group
Contact – Bobbie Minshull: 07714479320

Hexham Ostomy Group
Contact – Judith on 0796 7927286

Northumberland Cancer Support
Contact – members@northumberlandcancersupportgroup.co.uk

Nottinghamshire

North Notts Stoma Support Group
Contact – Tore and Nicky Norman: 01773 715460

Nottingham Colostomy, Ileostomy & Urostomy support group
Contact – Rosemary Brierley: 0115 9826691

Nottingham Stoma Support
Contact – Jenny or Kate: 01159627736/ Mrs B Heath: 01159663073

Don't forget your travel certificate this Summer

Contact CA office on **0118 939 1537** or email: **cass@colostomyassociation.org.uk**

O

Oxfordshire

Oxfordshire Ostomy Fellowship
Contact – Pat Longworth: 01235 524163

S

Scottish Borders

Stoma Support Group
Contact – Nancy Fraser: nancyfraser@talktalk.net or 01450 374012. Fiona Gentleman: r.gentleman@sky.com or 01450 371063

Shropshire

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

Staffordshire

Outlook
Contact – Moira Hammond 01782 627551

Suffolk

East Suffolk Ostomy Group
Contact – Marion Fisher: 01473 311204

James Pagett Ostomy Support Group
Contact – Sandra Hutchings: 01502 585955

West Suffolk & District Stoma Group
Contact – Jessica Pitt stoma nurse: 01638 515525

Surrey

Epsom and District Stoma Support Group
Contact – Lindsay, Trevor or Sheena: 01372 735925

Sussex

Brighton & District Support after Stomas (SAS)
Contact – Sylvia Bottomley: 01273 554407

The Ostomy Friends Group
Contact – Jane Quigley: 01323 417400 ext 4552

West Sussex Princess Royal Stoma Support
Contact – Tina Walker: 01444 441881 ext 8318

T

Teeside

Dales & Vale Ostomy Support Group
Contact – Carol Watson: 01677988150 / pcw-agw@tiscali.co.uk or Mr Simpson: 01677424877 / 07546259132 / rolandsimpson1945@gmail.com

Tyne & Wear

Gateshead Stoma Patient and Carer Support Group
Contact – Stoma Care Nurses: 01914453152 or email stuart.sutcliffe81@yahoo.com

W

Wales

Blaenau Gwent Self Help
Contact – Celia McKelvie: 01873 852672 After 6pm

Bridgend Ostomy Patients Support Group
Contact – Anita Brankley (Secretary) 01656 645602 or Pat Jones 01656 786103

C.A.S.S Colorectal and Stoma Suport Group
Contact – Colorectal Nurse Team on 0168 5728 205

Cwmbran Ostomy Support Group (COSG)
Contact – Pippa Lewis: 01633 791339/07504713069

Royal Glamorgan Stoma Care Support Group
Contact – Domenica Lear 01443 443053

Swansea Ostomy Self Help Group
Contact – Glynis Jenkins: 01792 418245

West Midlands

Coventry Stoma Support
Contact – Martin: 07947385643

Wiltshire

Swindon IA
Contact – www.swindon-ia.org.uk

Wessex Stoma Support Group
Contact – Michael Slater: wessex.stoma@yahoo.co.uk or on 0172 2741 233

Worcestershire

Kidderminster & District Collossus Support Group
Contact – Brendon Drew: 01299 400843

Y

Yorkshire

Acorn Ostomy Support Group
Contact – Michelle: 07580693155 (After 6:00pm)

Airedale Stoma Support
Contact – Sue Hall: 01535 210483

Barnsley Bottoms Up Stoma Support Group
Contact – Stoma Nurses 0122 6432 528 or Celia Utley (Chairman) 0122 6284 262

Behind You (Calderdale & Huddersfield Bowel Cancer Support Group)
Contact – Stoma Care Nurses: 01484 355062

Dewsbury & District Ostomy
Contact – Janet/Eileen: 0844 8118110

Leeds Bowel Cancer Support Group
Contact – Lynda Castle (Colorectal Nurse Specialist) 0113 2065 535

Rotherham Ostomates Caring Support
Contact – Karen Kilford: 07880575758

Scarborough Stoma Support Group
Contact – Sister Jean Campbell: 01723 342388, Amanda Rowe: 01723 342446

The Hull and East Riding Colostomy Support Group
Contact – Pete Smith: 07989 565335 or Pete Rennard: 07939 518642/01482793966 or Rosanna Grimsby: 01482801575. Website: www.hercosg.org.uk

Note: Information about **stoma support groups** is regularly updated in ***Tidings* magazine** and on the **Colostomy Association website.**

If you know of a **stoma support group** near you **not mentioned in our listings** please let us know. If you are interested in setting up a support group the **Colostomy Association** would be pleased to assist.

Contact the **Colostomy Association office:**
0118 939 1537

or **E-mail: cass@colostomyassociation.org.uk**

colostomy association

Thank you for your support

Regular donation

Your on going commitment means CA can plan its services with confidence safe in the knowledge that regular donations will be received. Help CA to reach out to more colostomates their families and carers to give support, reassurance and practical advice to those in need. With your help we really can and do make a difference - thank you!

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

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

My Details: Title: Name: Surname:
Address:
Postcode:
Telephone (home): Mobile:
Email:

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

To the Manager: (Bank or Building Society)
Bank Address: Postcode:
Name(s) of Account holder(s):
Account number: Sort code:
I would like to make a **regular donation*** of ☐ £15 ☐ £20 ☐ £25 ☐ £50 or other amount (please state) £
☐ **monthly** ☐ **quarterly** ☐ **annually starting on the** ☐ **1st** ☐ **15th** ☐ **25th of month:** **year:**
thereafter until further notice. *Please state your donation amount in words:
(Please cancel any previous standing order in favour of this beneficiary).
Please pay: **NatWest Bank, Market Place, Reading, RG1 2EP**
Account name: **C.A. Ltd** Account No: **88781909** Sort code: **60-17-21**
Name: (IN CAPITALS)
Signature: **Date:** / / 2014

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Signature: **Date:** / / 2014

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

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

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

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

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