

Tidings

Helping **ostomates** since 1967



**Not all
disabilities
are visible**



#stomafriendly

What we've learned so far...



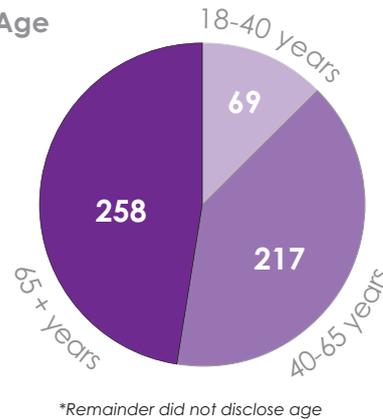
A SMALL PART
OF A BIGGER LIFE.

We had 547 responses to our 'living with a stoma' questionnaire from people living in Northern Ireland and the Republic of Ireland.

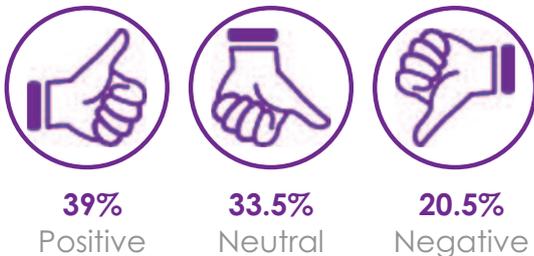
Gender



Age



Positivity of words to describe your life since your stoma surgery



93 % responded to this question

Colostomy specific responses to words to describe your life post-surgery

< 2 years post-surgery: **49.3% negative words**

Most popular word: **RESTRICTED**



3 - 5 years post-surgery: **26.9 % negative words**

Most popular word: **FREEDOM**

Help us understand how you feel...

The Eakin Group, founded by pharmacist Tom Eakin forty years ago, manufactures and sells stoma care products worldwide from a purpose-built factory in Northern Ireland and within the UK via Pelican Healthcare.

As shown above, previous research carried out looking into the psychological impact of living with a stoma highlighted a lengthy adjustment period of up to 2 years for many people following colostomy forming surgery.

We are keen to extend this research within the UK and Ireland to ensure we gain a comprehensive understanding of the reality of living with a stoma and apply this information to improve both education and stoma care products. We want to make sure new product developments not only function as required but also promote health and well-being.

For those willing to help with this research, we are looking for people who have a stoma and are living in the UK/Ireland to complete a short questionnaire to help us understand their daily stoma care. There is also an additional opportunity to help with new product developments by volunteering to evaluate our latest products. We would be delighted to accept anyone who is willing to help with either research or product evaluations or indeed those who are interested in both areas.

If you are interested in helping us either with research or by providing product feedback, then please contact us by phoning:
UK - (028) 9187 1000 | ROI - (01) 679 4400
(Mon-Thurs 8.30 am- 5.00 pm, Fri 8.30 am- 2.00 pm)
or email research@eakin.co.uk

Our Clinical team will be more than happy to provide you with more information. By participating, you are really helping us to develop new ostomy products which will greatly improve the quality of life of anyone with a stoma.

When you contact us, we will be discreet and anything you tell us will remain completely confidential.

We will not use your personal information for sales, marketing or any promotions and we will not share your personal information with anyone else.

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Cover picture

Stoma Aid: One year on
 (see pp28–29).
 (photograph taken by Ian Jackson)

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Tidings Magazine:

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dear READERS

Thank you to everyone who raised awareness of what it's like to live with a stoma, by speaking out or remaining silent on Colostomy Day. On our centre pages, you can see the many events which took place all over the country. I promised to mark the day by sitting silently in some public place reading *Tidings*. The place I chose was a bench in the local park, so I could keep an eye on my youngest granddaughter on the swings and slide in the playground.

But surely, I hear you say, as editor you know exactly what's in *Tidings* ... you don't need to read it! Well, I was trying to see the magazine through your eyes, the eyes of the reader, and consider the suggestions you made on the questionnaire many of you completed recently. Some of these have already been implemented. You wanted more emphasis on the early days of living with a stoma, so in this issue we have an extract from Fiona's blog in which she describes her shock when she faced life-changing surgery. Janet writes about how she felt before the operation and in the three months after surgery. Len describes how he overcame his reluctance to travel by taking short holidays in the UK before venturing abroad.

Some of you felt there were too many stories about people whose stoma was formed due to cancer so the remainder of the stories are from people who had their colostomy for other reasons. Derek has had a colostomy for 63 years; it was formed when he two days old, as he was born with a condition called imperforate anus. For others it was to improve their quality of life. Jean sustained damage to her sphincter muscles during childbirth. Frances opted for a stoma after many years of suffering from bowel problems due to endometriosis. She lives in Scotland, which should please readers who commented that there was not enough input from people who live up north. There's also a strong Scottish influence on the fundraising page and our local support group is from West Lothian.

Irrigation is, for many, the perfect way to cope with a colostomy. Some readers, however, especially those whose condition or circumstances mean that irrigation is not possible for them, felt that there is too much emphasis on this topic in *Tidings*. Sarah Squire acknowledges this on the irrigation pages and includes quotes both for and against this form of colostomy management. The editorial team, however, all agreed that it is important that this section remains in every issue of the magazine, to ensure that all those who have not heard of irrigation are aware of it, and its potential for making a colostomy easier to manage.

It's now fifty years since volunteers of the Colostomy Welfare Group began visiting patients while they were still in hospital following stoma surgery. On 16 September 2017 the **Colostomy Association** celebrates the anniversary of our foundation. Turn to pages 16 and 17 to find out our plans for this special day and how to reserve a place.

Please do keep sending us your letters and e-mails. Rest assured that we will not print your name unless you give us permission. Some of you may have wondered about the retired journalist who wrote for us in the last issue. Who was it? We were unable to print his name as we did not have confirmation that we could do so. By the time it arrived *Tidings* had already gone to press. I would like to acknowledge here that it was Richard Ingham who wrote *There's Humour in a Tumour*.

Finally, I'd like to leave you with a quote from a *Tidings* reader that I feel sums up how many of you feel about the magazine: "Other people's experiences help to put one's own problems into perspective...and sometimes provide solutions."

Happy New Year to All

Rosemary

Rosemary Brierley
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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:
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 Enterprise House, 95 London Street
 Reading RG1 4QA

By telephone:
General Enquiries: 0118 939 1537

Stoma care queries only:
Freephone Helpline: 0800 328 4257

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

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

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

inside this issue

all your regulars & special features

Cover Story

- 28 **Stoma Aid**
One Year On

From Health Professionals

- 43 **Granulomas**
Julie Rust explains
- 44 **Dear Nurse**
Julie Rust answers readers' questions

Real Lives

- 8 **Fifty Years Plus**
Derek writes about his life with a colostomy
- 11 **A Difficult Decision**
for Frances
- 12 **Collen and I**
Jean explains how a colostomy improved her quality of life
- 21 **Three Months Down the Line**
Janet talks about the early days with a stoma

Living with a Stoma

- 7 **Everybody Poos...**
Fiona Munro's Blog
- 22 **To Irrigate or Not to Irrigate**
Sarah Squire asks the question
- 34 **Travel Tips**
- 35 **Holidays Since my Operation**
Len ventures further afield

CA News

- 14 **Purple Iris Award**
- 16 **Colostomy Association 50th Anniversary**
16 September 2017
- 19 **Fundraising**
A thank you for your generous donations and fundraisers
- 25 **Picture This**
Enter the 2018 Calendar Competition
- 30 **Colostomy Day**
A Thank You to everyone who took part

Support

- 37 **Junior Ostomy Support Helpline (JOSH)**
- 39 **The Breakaway Foundation**
- 41 **Facebook**
- 47 **Readers' Writes**
Your letters and e-mails.
- 50 **A Local Group in Scotland**
GOSH (Group Ostomy Self Help)
- 51 **Events at Local Support Groups**
Shropshire Open Day
- 56 **List of Local Support Groups**

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“Everybody Poos...”

Everybody Poos... but not everybody poos in the same way...

Ovarian cancer. Surgery. Chemotherapy. Hair loss. Wheelchair. Intensive care. Terminal. Incurable. Remission. So many words and phrases have entered my world in the last year. Some have been easier to deal with than others. But one word stands out because I'd never heard it before.

Colostomy

I didn't even know what a colostomy was... No one in my life had ever mentioned this word before. After some questioning and research, I discovered 'colostomy' meant life changing surgery. I was so confused. Why would I need this surgery? I didn't have bowel cancer. I had ovarian cancer...

Turns out, however, that ovarian cancer doesn't much like to hang around in just the ovaries. It likes to spread to other organs and, in my case, it was now sitting on the surface of my bowel and would need cutting away.

In the days that followed my approval for this surgery I had many appointments seeing stoma nurses. I was handed leaflets I couldn't bring myself to read. I had conversations I didn't listen to. My abdomen was marked for the 'exit site'. I was in complete denial. This couldn't be happening. Hadn't cancer already done enough?

In the days following surgery I faced an 18-inch scar. Drain sites. Drips. Syringe drivers AND a stoma...another alien addition to my ever-changing body. As the days turned to weeks slowly these additions diminished. The drains were removed. The scars started to heal. The drips were wheeled away. But one thing remained. The colostomy wasn't going anywhere. It was a permanent feature.

It was hard to come to terms with. It felt like the final shred of dignity I had left had been removed. I no longer had control over my bodily functions. In a 'normal' body you are able to control when you poo using the muscles in your anus. Your colon, however, doesn't have muscles that you can consciously control. So if you have a stoma your body excretes waste whenever it wants. Any time. Any place. No warning. No control. Great!



So I learned that I'd now need to carry spare 'colostomy bags' with me wherever I went so that if my bag filled I could change it. I'd also have to carry wipes and bags to dispose the waste in. No more small handbag for me!

I was given a special card stating that I had a medical condition that allowed me to access any toilet anywhere – one small perk.

And also a special 'RADAR key' that allowed me to unlock any public toilet 24 hours a day 7 days a week – OK another small perk.

I was taught that I could no longer wear button up jeans as they'd cut off the bag and prevent it from working. Instead I would have to wear high-waisted jeans or jeggings. I also couldn't wear tight fitting dresses. Wait, you mean I have an excuse to buy a whole new wardrobe. No questions asked. Things were starting to look up!

Whilst it was hard to come to terms with at first, I began to realise that this was a result of life enhancing surgery. Would I, if given the chance, turn back time and say "no wait actually could you just leave that cancer in my bowel I'd rather not have a stoma"? Hell no!

Of course there are still hard times!

Like when I go to use a disabled toilet and I'm judged by observers because I don't 'look' disabled.

Or when I use a toilet and there is no bin. No one wants a bag of poo left on the toilet floor!

Having an upset tummy is the worst! Usually when you have an upset tummy you give yourself enough time (hopefully) to get to a toilet. Not with a stoma. With no warning – that waste is making an exit whether you like it or not! If your bag sticks in place great. If not, then all hell is breaking loose wherever you are! I'm not going to lie – I've had a few what one of my nurses affectionally refers to as a 'Code 20' incidents. I've learned that having a dark sense of humour helps.

What also helps is people sharing their story about their colostomies. Did you know 1 in 500 people in the UK have a stoma? And not just because of cancer. Sometimes because of Crohn's disease or even from child birth!

With this in mind I'm pretty sure you know someone else with a colostomy bag! But there is still so much stigma attached to discussing 'poo'.

So what can we do?

We can celebrate the differences in our bodies.

We can stop being embarrassed by our bodies and what they do.

We can stop body shaming.

And, most importantly, we can stop taking everything so seriously...after all everybody poos just some of us are lucky enough to be able to do it 'on the go'. See, I told you a sense of humour helps.

Fiona Munro

Taken from Fiona's Blog

"Surviving (With) Cancer @fkmunro lessons from a cancer warrior"

If you would like to follow Fiona's Blog you can find it at <https://fkmunro.com/blog/>

Fifty Years Plus...



Derek as a baby, with his big brothers and sister and with his parents

I have just received the latest edition of *Tidings*; it says that the **Colostomy Association** has been helping ostomates since 1967. By that time, I'd had my colostomy for 14 years but no one told my parents about the Association. Of course, life was very different then; no one talked about stomas. We just had to cope.



On 2 January 1953 I was born with a clubfoot and only one kidney. I also had a condition known as imperforate anus, so when I was two days old I had to have surgery at Nottingham Children's Hospital to form a colostomy. This operation saved my life.

My parents told me that I spent the first six months of my life in hospital. There were no stoma nurses in those days and when I came home my parents were just left to get on with looking after me. Of course, there were no stoma bags either and I had to wear a pressure bandage and my skin had to be protected with aluminium based barrier cream. The stoma was very low and to the left, which made the bandage hard to change, and often my clothes had to be washed due to soiling. My brothers and sister were brought up with me having a stoma and my parents always treated us all the same.

When I was five, I had to go to school like everyone else, but my parents insisted I attend the nearest school to my home so that I could come home at lunchtime every day. My mother used to use an irrigation form of equipment to clear out my bowel. This would make it easier for me to attend school for longer periods of time.

If I had a bath or shower, the cotton wool and bandage had to be taken off, not a good idea as my stoma was very active, but I had no choice. There were no plastic disposal bags or medical waste collection in those days. My parents had to burn the soiled dressings in the fireplace; this went on for a few years until the hospital decided they would incinerate the waste and they gave us plastic clinical waste bags which the local council collected once a week.

The family never wanted me to tell anyone at school about my stoma. After I left junior school, doctors prescribed a kaolin and



Derek with Kate and Jenny, his stoma care nurses at Nottingham City Hospital

morphine drink, to slow down my output. This was in the 1960s when schools had their own doctor and nurse; when they found out they stopped my medicine as they said it was not good for me. I have been taking codeine phosphate ever since. I went to hospital out-patients every year but I still only had pressure bandages with absorbent cotton wool to cope with my output.

Then, when I was around 12, I was sent to Sheffield Children's Hospital because they thought they could operate to change me. My parents met a specialist and then I went on my own for a few months for tests. The operation, however, never took place because I think the surgeons told my parents it was too dangerous. I was sent home and a stoma nurse came to see me and brought a foam ring and a stoma bag on an elastic band but, because my stoma was so low down it would not collect the waste; it just leaked everywhere. I went back to school still using pressure bandages and came home every lunchtime to change them.

It was not easy to find work when I left school. Companies did not want to employ people with disabilities in those days. When I was 15 I went to a Government Rehabilitation Centre to see what could be done. My doctor told me I should look for work as that would be better than sitting at home.

Finally, in 1969 when I was 16, I found work. The company took a chance with me and I went on to be an engineer with the firm and have stayed there ever since. As I still wore a pressure bandage, there were times when I had to go home to change my clothes. If I had diarrhoea nothing could stop the soiling of my clothes. I still went to hospital out-patients once a year, the only thing that changed was the types of cream they gave me to try to reduce the skin soreness. I was told nothing could be done for me and just to live my life as best as I could. I was discharged and didn't go back until I developed kidney stones.

It was around five years ago that I went into hospital to have kidney stones removed. I had to stay in for a few days and the nursing staff sent for the stoma nurse to visit me in the ward. I was still using pressure bandages with cotton wool. They told me they had never known a stoma like mine: the skin around my stoma was deformed and had sores, which could not heal, no skin in some parts. They said I needed an operation to change my stoma.

I started going to the stoma clinic at Nottingham City Hospital. The Nottinghamshire & Derbyshire IA helps to run this clinic and provides support and advice about living with a stoma so I joined the IA and have been a member ever since. I know there is a difference between an ileostomy and a colostomy but we all have a stoma. I enjoyed the clinic so much I go every month if I can. The stoma nurses, Kate and Jenny make a great effort for us, always there to help with advice about any problems we might have.

The nurses showed me the stoma bags that are used today, but these bags did not fit because of where my stoma was placed and caused problems with skin irritation on my leg. I was first sent to a skin specialist who told me the only way the skin would recover was to have an operation to move my stoma.

The colorectal surgeon also said he never seen anyone like me and he would change my stoma position and the way it worked to give me a better life, so in May 2013, at the age of 60, I had the operation. The surgeon had told me it would not be easy. He said that when I was growing up, my body became stretched inside and I should have been operated on years ago. However, that was the 60s and medical knowledge is far better now. I spent 17 days in hospital and had to take five months off work.

The operation made a great difference to the way I live my life now. Compared to the

previous 60 years, it is totally different not having to worry about clothes being soiled; the stoma bag now works, making it easy for me. The surgeon also gave me a mucous fistula below my belly button. I use a small cap to collect the small amount of mucus that comes out. One side effect is that, due to the operation and my age, I now have a hernia which I have to live with.

The stoma nurses at the Nottingham City Hospital clinic have done a lot for me, pushing me to have the operation that would change my life. They were right – it has changed my life. Now that I have a stoma bag and my colostomy works a lot better, I have learnt to swim. I also visit the gym which has a set routine for me that I would never have been able to do before. Work is better now, no worrying about what might happen. I go abroad on holiday with confidence. It is a shame my parents never saw me like this.

Having a colostomy does not mean the end of our life. We can achieve most things. I have had a stoma all my life – over 63 years. Things have changed, medical knowledge is far better now than when I was born all those years ago. Products are very good and stoma care nurses are there to help us with any problems. We have support from the national organisations like the **Colostomy Association** and IA, local groups and a presence on the Internet via Facebook or Twitter.

My life has changed so much since my operation to move my stoma. The way it works is now is so much better; I wish I'd had the procedure years ago. I feel so different it's hard to believe what my life was like all those years ago.

The stoma nurses kept encouraging me to have the operation. Kate and Jenny said it would change my life; they were correct in what they told me.

I am grateful that I did listen to them!

Derek Icke

With the **Colostomy Association** 50th anniversary celebrations approaching we would like to hear from anyone who has had a colostomy for half a century or more. If you, or someone you know, had stoma surgery before the Association was founded please get in touch via e-mail to

editor@colostomyassociation.org.uk

or a letter to:

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A Difficult Decision

In the Summer issue (*Tidings* 42) we published an article about the Double-barrelled Wet Colostomy and John's story of what it's like to live with a stoma which has two openings, one for faeces and one for urine.

Frances wrote to thank us for these articles which helped her decide whether or not to have the operation to form this type of stoma. Here is her story:

I am a retired nurse and have always had painful monthly periods, but thought nothing of it. Over a number of years, they became heavier and more painful, but I didn't seem to find the time to go to the doctor. It was only when I was visiting my Mum in hospital and I had so much pain that I thought: "I should be in that bed." This spurred me on to see my GP on the Friday, and on the Monday I was in hospital to have what was thought to be an ovarian cyst removed. After the operation, the surgeon told me that I have severe endometriosis and said, "It looked like a bulldozer had been let loose in your abdomen."

Once I had got over that operation, I went on to have a hysterectomy and the removal of my ovaries. I was not too concerned as I thought that I could still look after my 30 pet animals and continue horse riding. I was wrong as I was in severe pain especially when I went riding, and every time my bowels moved. The next surgeon I saw suggested that I have my sigmoid colon removed. This helped for a few years, but then even passing faeces became painful. When my new surgeon did a colonoscopy, she had to give me a general anaesthetic as, despite being sedated, I just about jumped off the table when air was introduced into the bowel. The next step was an MRI scan, which showed multiple adhesions attached to the bowel. The only way forward was a colostomy.

As you can imagine, fellow ostomates, this was a complete shock. How was I going to look after my animals, clean out the cages, lift bales of sawdust, carry sacks of food for my sheep, hold them steady to treat foot rot, and carry full pails when changing the water in the fish tanks? How was I going to tack up and ride my horse, Mia, and lift her feet to clean them? All this was going through my mind, but pain won and I



agreed to a colostomy. My only sadness was that my surgeon said that I could no longer keep sheep, as the physical strain of working with them could cause a hernia or a prolapse of the bowel.

Before my operation, I saw some super stoma nurses who prepared me well by showing me products and helping me to choose, putting me in touch with a delivery company and arranging for me to receive *Tidings*, this wonderful magazine. When I awoke from the operation, it wasn't too much of a shock and I found I adapted quite quickly to having a stoma. The stoma nurse helped me choose a drainable bag. This was because my stoma was high up in the colon so the output was fairly liquid which meant a closed bag would fill up fairly quickly and I would have to change it four times a day.

My family were super. At first I had a few leaks. My husband was especially supportive, as the leaks often happened at night and he helped me change our bed and get washed. My daughter suggested I carry spare clothes and baby wipes in the car, in case I had leaks while away from home. To protect my skin, I use adhesive remover when removing the pouch and if it becomes sore I use Cavilon sticks. I continue to ride and look after my animals and have found it does not affect my life too much – or so I thought.

After two years, my colostomy prolapsed about 18 inches and became very swollen. Much to the amusement of the nurses, the prolapsed part of my bowel was put in a plastic bag and, every three or four hours, it was covered with icing sugar in an attempt to bring down the swelling. Unfortunately, it did not work and I am now the proud owner of an ileostomy.

My endometriosis continues and two years ago I had a procedure to insert a suprapubic catheter. This is normally carried out by keyhole surgery but the surgeon said that in my case it would have to be open surgery because of the adhesions.

After a year of urine infections and more pain, I wondered whether I should have a urostomy instead of the suprapubic catheter or perhaps even a double-barrelled wet stoma. However, after he saw both my abdomen and bowel, my urologist was not keen to do either. My GP and my brother and my sister-in-law (both GPs) also advised against it. The recent *Tidings* article "One pouch instead of two" helped me understand what was involved and realise they were probably right.

Life goes on. When my friend was competing at a riding event in Ayrshire I went along as honorary groom, and we both camped overnight in the horsebox. We had a hob where we made our bedtime hot chocolate and porridge for breakfast. I slept on a shelf over the cab and during the night, had to climb down the ladder and trudge across the field to get to the toilet. Who says you can't do whatever you want when you have a stoma? ■

Medical Terms Explained

Suprapubic Catheter

A thin tube which drains urine from the bladder. It is inserted into the bladder through a small hole in the abdomen. It may be needed by people who have urinary incontinence (leakage), urinary retention (not being able to pass urine) or another medical condition.

Coleen (my colostomy) and I

My health problems started during my first pregnancy. I had very high blood pressure right from the start, and had to give up work and rest. My baby was expected on 11 July 1965 but on 23 June, after attending the pre-natal clinic, I was told I had toxæmia and to go straight to hospital. I was induced two days later and went into labour at 9 o'clock that evening and do not remember anything until 3 o'clock the following day. My daughter, Heather, had been born at 12 noon. I did not see her for two days.



After the birth, I needed a blood transfusion and had to have all my stitches cut because I had a massive haematoma. I should have been re-stitched after ten days, but I had not healed up so another week went by before I was stitched again. I was in hospital for three and a half weeks. When I did come home, I experienced lack of bowel control and was having accidents when I went out. In September, I went to see my GP who informed me I would have to have a 'repair job'. This op was carried out in January, but when I came home I was still having trouble with my bowels and also experiencing intimacy problems. I went back into hospital in June to be cut and re-stitched once more.

We did want another child, so when I went for my last check-up I mentioned this to the doctor. He said it would be fine, although I would have to have a Caesarean section for any future children. We went ahead and while I was having a pre-natal examination

the nurse happened to say that I was very brave to have another baby after everything I had been through. I told her that I was having a Caesarean this time. The doctor who was examining me didn't agree and said that they'd see about that when I was 36 weeks. I was really worried by then and, to give my husband his due, he went to see my GP, to explain the situation. The doctor arranged for me go into another hospital.

I gave birth to my little boy, Stephen, on 3 January 1968 and was told by the surgeon who delivered him that I must have another repair as I still hadn't healed from the last two ops. As my parents were quite elderly, I could not ask them to look after two children so put it off. In the meantime, as my muscles were so lax, my method of contraception failed and I soon fell for my third child, Gillian, a lovely little mistake. She was also born by Caesarean section and all was well, but I was told that I needed another repair. So, when she was six months old, I went in to hospital again

and then for two weeks' convalescence at St. Leonards-on-Sea.

Despite all these operations the doctors still thought I would eventually have to have a stoma; my husband said: "If you have that, I shall leave you." As it turned out, however, he wasn't the one to leave.

There had been a lot of domestic abuse in our marriage so in April 1971 I left my husband, taking my three children with me, and moved back to my home town of Broadstairs. I can assure you that no-one walks out on a marriage unless they are desperately unhappy. You have the guilt at what you have done for your children plus the emotional side and the lack of money. The alimony was seventeen shillings and six pence a week for four of us. Five years later we were divorced on the grounds of my husband's unreasonable behaviour. I did receive half the proceeds of the sale of the house, not enough to buy another home at that time, but I did manage to keep a bit by for a rainy day and the children were able to go on holidays with the school.



Before I moved back to Broadstairs, I rang my old boss; he had just bought a sweet shop in the High Street and he offered me a job and the flat above, if I wanted it. I couldn't believe my luck. The flat was very large and spacious, but oh so cold in the winter, as I only had one gas fire to heat it. I could only bathe the children once a week; on the other evenings, I had to fill a bowl with hot water to give them a good wash down.

Whilst living in the flat, I was still experiencing bowel problems and went to my local GP who advised that I go to see a specialist at Margate Hospital. On examining me, he said he could see what needed to be done, but he couldn't do it. There was only one man in the world who could do the operation, but I would need to go to London.

He sent me to St. Mark's Hospital which, in those days, was in City Road, Islington. It was a wonderful hospital, very antiquated but the treatment and care patients received was second to none. It was such a happy place where we all did a lot of laughing despite our illnesses. I was in St. Mark's four times in all. Being a bowel hospital brought us patients all together, so to speak, and they say that laughter is a tonic; well it certainly was. Sadly, the old building has now been pulled down as the hospital moved to Northwick Park.

In 1985, I was in St. Mark's again for three weeks for what turned out to be the last repair before it was decided to give me a colostomy. I won't go into all the gory details of that op but it was very demoralising. I was to take 'Epsom Salts' three times a day, for three days before the op and for ten days afterwards; each lunchtime the surgeon told the nurses to give me a glass of sherry!

In the end, I was sent for balloon tests to see how much muscle was working, which turned out to be nil. Sir Alan Parks, the surgeon, did explain to me that when I had my first baby, the doctor who delivered her literally pulled her out and therefore tore my anal sphincter muscles in half and that is why I had no control. In 1988 when I was 52, I had my colostomy formed. I called her Coleen, and have never looked back. I think, because I knew I was going to have the operation, I accepted the fact that I would have to live with a colostomy for the rest of my life. I must admit it was much better than before I had the operation.

I wear a two-piece system by ConvaTec. I can now go out without fear of having

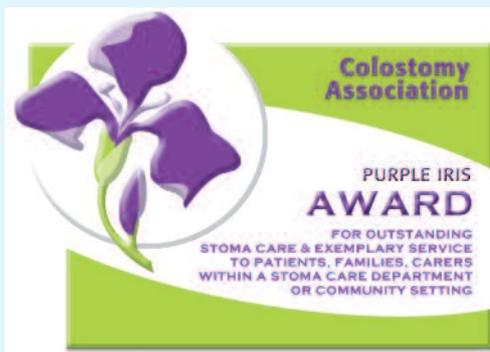
an accident and this gave me the confidence to go on a coach trip to the Black Forest with a friend. In the 90's my son went back-packing and met a lovely Australian girl who is now his wife. In November 1997 I flew out to Australia for their wedding and my son's birthday on 3 January and returned in February. The colostomy was no problem to me on the flight, and I coped with everything very well whilst there.

Since then I have been back to Australia three more times. On one occasion when I was staying with my daughter-in-law's parents we took a trip to the Murray river and whilst there I discovered that I had packed my stoma supplies but left them in the toilet at their home back in Adelaide. Fortunately, they knew someone who was training to be a doctor at a local hospital so we were able to get some supplies from there. Another lesson learnt!

At the age of 74 I developed bowel cancer and, although the surgeon had removed the tumour, he decided I should take chemotherapy tablets, which proved to be too strong, resulting in a heart attack. Fortunately, I have recovered and am in fine fettle now and enjoy my life. I belong to Stevenage Ostomistics stoma support group and I enjoy their meetings and outings very much; they are a really friendly crowd.

Although I have had my ups and downs I consider myself a very lucky lady. I have three lovely children, six grandchildren, lovely relations and many friends. So, all in all, I feel blessed.

Jean Andrews



Colostomy Association Purple Iris Stoma Care Award

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

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



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

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

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

We welcome nominations for stoma care teams who:

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

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

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

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

Your details

First Name: _____ **Surname:** _____

Address: _____

_____ **Post code:** _____

Telephone Number: _____ **Email:** _____

Nomination details

Name of team/department: _____

Name of hospital/community setting: _____

Reasons for nomination: _____

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

Additional Information

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

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

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

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



“Worrying less about leakage makes things so much easier”

For 65-year-old Henry, Brava® Protective Seal is the missing link in his ostomy solution. It gives him a feeling of security and helps him live a life without restrictions.

After his operation in 2008, Henry adapted quickly to life with a stoma: “It has been very easy to live with – easier than I thought.”

Indeed, as someone who has always been active, Henry’s biggest challenge was taking it easy during his rehabilitation!

But after some time, he began to experience occasional leakages. These left his skin around the stoma irritated, so his stoma care nurse recommended he use a seal. Henry tried many types, but preferred Brava Protective Seal.

Henry was also impressed with the seal’s additional benefits. He explains: “It’s easy to apply and remove without leaving much residue.” In turn, the lack of residue also made it easier to maintain healthy skin. He continues: “residue has to be scraped off and that can irritate your skin.”

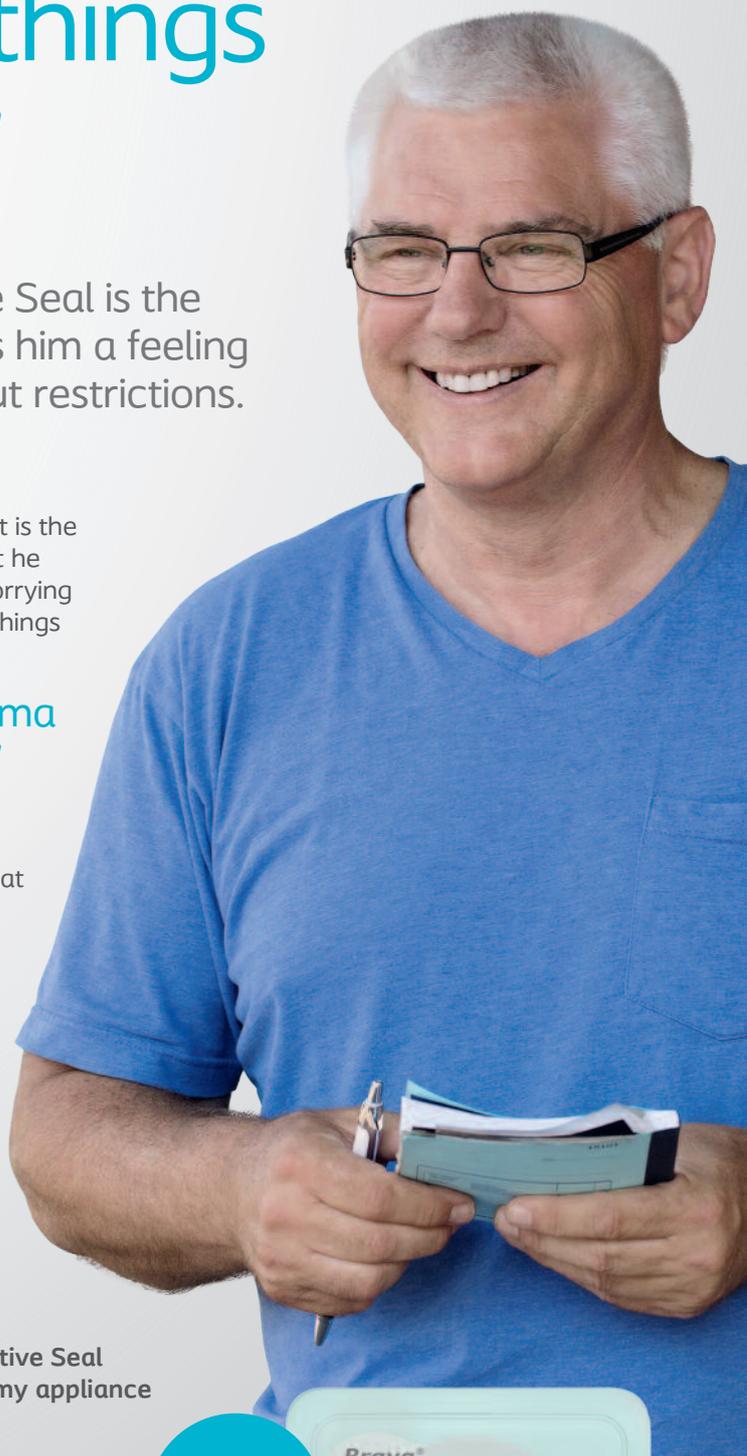
For Henry, who works at a brewery, the biggest benefit is the feeling that he can do what he wants, when he wants: “Worrying less about leakage makes things

“I don’t give my stoma a second thought”

so much easier. I’m a very active person and I think that keeps me young.”

Whether he’s working or playing one of the sports he enjoys, Brava gives Henry the feeling of security and confidence he needs: “I can travel, I can drive and I can live a normal life. I don’t give my stoma a second thought.”

Henry uses Brava® Protective Seal with a SenSura® Mio ostomy appliance



Dual-protection

Protects against leakage and absorbs skin moisture.



Easy to handle

Fits snugly around the stoma. Can be applied over skin with dips, creases and folds.

NEW



Brava Protective Seal with NEW polymer formulation.

50th Anniversary

Join us on Saturday 16 September 2017 at Wokefield Park in Mortimer near Reading for our Open Day, 50th Anniversary celebration and Fashion Show. We're going to be looking back at our origins as the Colostomy Welfare Group and at all the great things that have been achieved since then. We're also going to be sharing our vision for the years ahead. Don't miss out on what promises to be a special occasion, so book your place now to avoid disappointment.

Our History

Our 50 year history is fascinating and we owe a huge debt of thanks to Gertrude Swithenbank and Frances Goodall. It is purely as a result of their foresight back in the 1960s that led to the creation of our charity as it exists today. Our research into the past has certainly revealed some interesting facts so look out for more information about those discoveries in the coming months!

Open Day

In a day packed to the brim, there will be the chance to meet and make friends with fellow ostomates, listen to topical talks, find out about the latest stoma products and arrange an appointment with a Securicare stoma care nurse. With around 20 exhibitors in attendance, various manufacturers' prize draws and our own celebrations, there is something for everyone. It will also be a great opportunity to speak to our volunteers from across the country, along with our staff, trustees and president. In fact, packing everything in is going to be the challenge. There will even be a 'meet and greet' area for people attending alone, so there's no excuse to stay at home!

Fashion Show and Three-Course Dinner

Colostomates of all ages will be gracing the catwalk, modelling a range of outfits from casual to formal or, some might say, downright glamorous. If you want a taster of what might be in store, then please visit our website for a clip of our magical 2015 fashion show.

After the fashion show it will be time to enjoy a three-course meal. This will be a 'jacket and tie' affair, with tickets for the whole evening costing £25 per person. This is a subsidised price and includes some wine. There will be ten people to a table. The menu will be revealed on the night, but if you have any special dietary requirements don't worry, just let us know on the booking form.

The dinner will be followed by a presentation ceremony for several awards, including volunteers' contributions and our beautiful Purple Iris stoma care department award. (So please remember to nominate your team if you feel they have given you exemplary stoma care.)

Outline of the Day

You can attend for all or part of the day and the only cost is £25 for the fashion show and evening meal.

| | |
|---------|---|
| 9.30am | Registration and light refreshments Opportunity to view exhibitors' stands |
| 11.00am | Official Welcome to 50th Anniversary Celebration and topical talks |
| 12.15pm | Lunch and time to view exhibitors' stands |
| 2.15pm | Talks including: <i>Parastomal Hernias</i> – by Mr Neil Smart, Consultant Colorectal Surgeon, Royal Devon & Exeter Hospital |
| 3.00pm | Time to view exhibitors' stands Prize draws |
| 6.30pm | Public bar opens |
| 7.00pm | Fashion Show |
| 8.15pm | Three-Course Dinner |
| 11.30pm | Close |

The fashion show is being sponsored by Dansac, with Yvonne Frost (Image-On) acting as image consultant. We extend our special thanks to all our current sponsors.

Accommodation

The conference centre, hotel and mansion lie within 250 acres of scenic grounds. Reduced rates are available for the nights of Friday 15 September 2017 and Saturday 16 September 2017, but only up until the end of February 2017 so book early! The hotel also boasts a mini gym and swimming pool so why not make a weekend of it? For an additional cost, other activities on the site include a high wire course, climbing wall, lazer combat and a beautiful 18 hole golf course, making it an ideal location for the whole family!

To book overnight bed & breakfast accommodation, please contact the Hotel Reservations Team direct on 0118 933 4100, quoting code: "COLO150717" to obtain the discounted price of £91.20 inc



VAT (single occupancy) and £108.00 inc VAT (double occupancy). Please note, rooms must be booked by the end of February 2017 as they are only being held until then and, once booked, rooms are not transferrable or refundable.

Post-Event Publicity

Staff will be taking photographs throughout the day to publish in our magazine, on our website and in social media. The press may be present too, as we hope to feature in the local newspapers. We also plan to take video footage again this year to provide a permanent 'movie' record of our 50th anniversary celebrations for use on YouTube and our website.

Book Now!

Please complete the booking form on the next page and return it to the office no later than 31 August 2017, but the earlier the better to guarantee your place(s) Around 300 people may attend, so please hurry to avoid disappointment! Hope to see you there!

For more information about the venue and the golf course please visit: www.devervenues.co.uk/en/venues/wokefield-park/

For more information about the outdoor experiences please visit www.uniqueoutdoors.co.uk/

50th Anniversary Open Day 2017 and Fashion Show

Saturday 16 September 2017



Booking Form

I would like to attend the following **Colostomy Association** events at **Wokefield Park, Goodboys Lane, Mortimer, Reading, RG7 3AE**



(please insert the number of places required):

Quantity

| | | |
|--|-----------------------|----------------------|
| Open Day only | <i>Free of charge</i> | <input type="text"/> |
| Open Day, Fashion Show and Evening Meal | <i>£25 per person</i> | <input type="text"/> |
| Fashion Show and Evening Meal only | <i>£25 per person</i> | <input type="text"/> |
| I enclose a cheque made payable to 'CA Ltd' totalling | £ | <input type="text"/> |

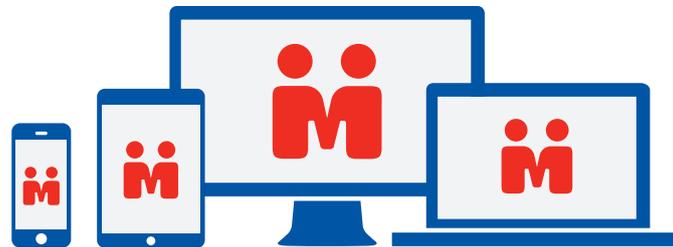
| | | | |
|-----------------------|--------|-------------|-----------|
| Details: | Title: | First Name: | Surname: |
| Address: | | | |
| | | | Postcode: |
| Telephone (home): | | Mobile: | |
| Email: | | | |
| Dietary requirements: | | | |
| | | | |
| | | | |

NOTE: Please remember to book your own overnight accommodation if needed. Reduced rates are available for the nights of Friday 15 September 2017 and Saturday 16 September 2017, but only up until the end of February 2017 so book early!

Please return this form to: **Colostomy Association, Enterprise House, 95 London Street, Reading, RG1 4QA** no later than **31 August 2017**, but bear in mind places are strictly limited so it will be best to book early to avoid disappointment.

Official tickets for the Fashion Show and Dinner will be sent to you nearer the time.

NEW FOR 2017



EASIER WAYS TO ORDER THROUGH MEDILINK



Salts Medilink has always provided a **reliable and easy way to order ostomy and continence products** by Freephone, post or email. **And now, you can also order online with our exciting NEW website.**

The Salts Medilink website lets you place orders at any time of the day or night, **whether you're at home or on-the-go**, and remembers your order history so that you don't have to.

All makes of stoma, continence and urology appliances dispensed



24-hour operated **emergency helpline***



24-hour home delivery service after receipt of prescription†



NHS Electronic Prescription Service (England only)



Cut-to-fit, personal modification service



Urgent supplies without prescription (GP authorised)



Customer Care Centres nationwide



Stoma Care Nursing Service**



To register, simply visit www.saltsmedilink.co.uk and experience even more from Medilink today!



FREEPHONE*
0800 626388
or visit www.saltsmedilink.co.uk

Fundraising Focus

Loz's Challenge comes to an end



Great Scots!

There's a strong Scottish influence to our fundraising pages in this issue and we're incredibly grateful to a number of individuals and organisations that have supported us.



Edinburgh Academicals FC held a collection for the **Colostomy Association** prior to their home fixture with Marr in the Scottish Rugby BT national League 1. The collection took place in memoriam of **Colostomy Association** volunteer John Cochran who sadly and tragically passed away in 2016. The Club raised **£145** on a day which saw the home team victorious by 26 points to 20.

Meanwhile, **Adele Loughran** competed in the Great Scottish Run in October and collected **£150** on behalf of the **Colostomy Association**.

Emma Brander (pictured below) also entered the Great Scottish Run and managed to raise an amazing **£720!**



Ruth Mullineux (below left) took part in the Great Scottish Swim in August and her efforts to swim a mile in a freezing cold Loch were rewarded with donations of over **£500** to support Stoma Aid.



In issue 42 we told you about **Natalie Doak** who was going to take part in the Glasgow leg of the Colour Run 5K event with her sister, Debbie. The event took place on 17 July and in Natalie's own words: "We had a ball doing it, but the main aim was to raise awareness about the struggles we went through as a family after my mum had stoma surgery, and doing this was a great way to do it."



Did it work I can hear you asking??! The answer is yes, people who didn't understand the condition began reading about it, and it also raised awareness to what happened to my mum when family friends felt they couldn't ask during the period after her surgery". Natalie and Debbie managed to raise **£525** for the **Colostomy Association!**

The last few editions have also featured the build up to **Loz Tronic's** Saharan Challenge.



We're happy to report that in October 2016 she managed to trek 84 kilometres over two days in the Moroccan desert from Afra to Nakhra Dunes. While training for this spectacular event Loz has also managed to raise over **£600** for the **Colostomy Association**.

Get involved!

The **Colostomy Association** is looking for runners who have managed to obtain a ballot place in the 2017 **London Marathon**, and who would like to run on behalf of our charity.

We are able to provide them with a running top for training and for use on the big day, and help with promoting their efforts through social and local media.

If you have a place or know someone else who does and are interested in running for us please get in touch.



We are also on the lookout for keen athletes in all sports who might be interested in competing for us in the future. It doesn't matter if you're a runner, climber, walker, swimmer, footballer or cricketer. If you would like to know more please email our development Officer Giovanni Cinque at Giovanni.cinque@colostomyassociation.org.uk

CONTINUED ON PAGE 20, COLUMN 1

Annual Raffle

Thanks to everyone who purchased a ticket for our annual raffle. Sales exceeded an amazing **£14,000**.

The draw was made on Friday 30 December and the winners will be notified shortly after. A big thank you goes out to everyone who purchased tickets. Look out for details of our prize winners in the next issue.

Unity Lottery



It has now been a year since the Unity Lottery replaced our 500 Club and we are glad to say that not only is its popularity growing with supporters on a weekly basis, they are also winning regularly as well!

Members have the chance of winning a main prize of **£25,000** each week (plus a £2,500 donation to the **Colostomy Association**), as well as smaller prizes of **£5**, **£25**, and **£1,000**. Entry is only £1 per week and we receive 50p for every £1 ticket sold. You can join by completing the form on page 36 or online by visiting www.unitylottery.co.uk but remember to link to our Charity.

Thank you!

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

- ❖ **Meghann Hill-Bradley** and her relay team completed the Lincoln half Marathon and raised **£210**.
- ❖ **Margaret Smith** from Uxbridge held her 80th Birthday party in August and asked for donations to the **Colostomy Association** instead of gifts. Thanks to the generosity of all those who attended Margaret raised over **£600!**
- ❖ **Vivian Tansey** donated **£100** to Stoma Aid, while **Claudia Cotton** donated **£1,000** also to Stoma Aid.
- ❖ **The Waldrons Chapel Fellowship** donated **£50** to the **Colostomy Association**.

Grants and Trusts

We're glad to be able to report that several more charitable trusts have made donations to the **Colostomy Association** to support either our core services or specific projects. These include the Donald Forrester Trust, The Charles Littlewood Hill Trust and the Payne-Gallwey Charitable Trust.

Bangers and Cash!



The **Colostomy Association** has benefited thanks to the kind generosity of a second supporter who donated their car to Giveacar.co.uk

Giveacar is a not-for-profit social enterprise that can turn your unwanted car into cash for charity. They arrange free collection, then either sell your car at auction or scrap it with the proceeds raised going to your charity of choice.

If you need to get rid of an old car and would like to benefit the **Colostomy Association** at the same time, give them a call on 020 7736 4242, email support@giveacar.co.uk or visit www.giveacar.co.uk

Please don't forget to mention you'd like to donate the proceeds to the **Colostomy Association**.

Textgiving

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

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

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

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

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

STOP PRESS

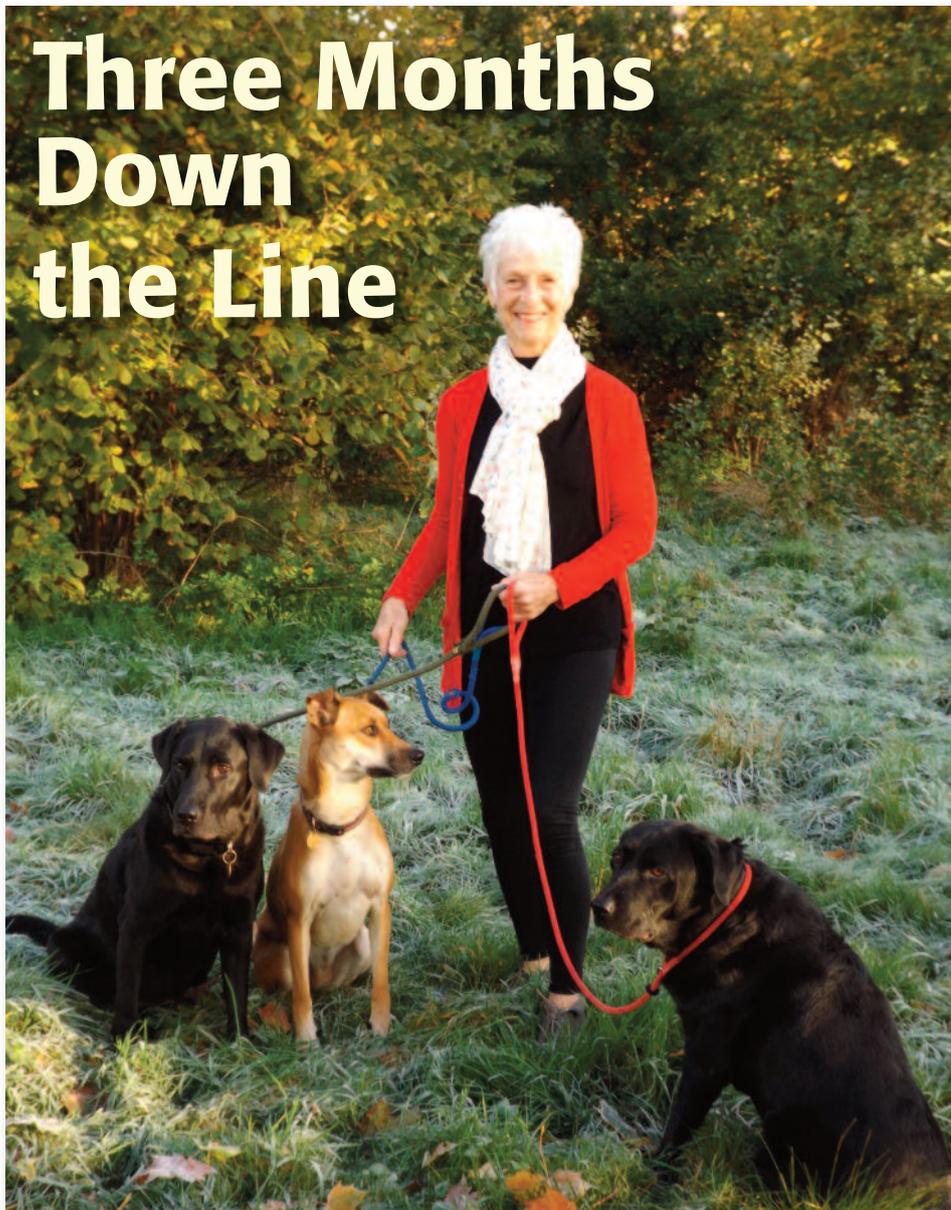
BREAKING NEWS FROM THE COLOSTOMY ASSOCIATION

- ◆ Following in **Asda's** footsteps, and on the back of the **Crohns and Colitis UK** campaign, **Morrisons** have now changed all the signage to read 'not every disability is visible'. **Well done Morrisons!**
- ◆ One of our supporters, Lesley Ann Cairns, recently contacted us to let us know that she was challenged using an accessible toilet at her local **Mecca Bingo**. Even though the incident was very upsetting there has been a positive outcome as Mecca Bingo has changed the toilet signage at the club. **This is great news!**



- ◆ Based on your feedback we have written again to **Marks and Spencer** to encourage them to change their accessible toilet signage to make people aware that not all disabilities are visible. We will keep you updated.
- ◆ In December we attended the Birmingham Children's Hospital Christmas party for children affected by bowel and bladder conditions. We took lots of cuddly Josh snow leopards along too. Each child was able to take one home as a reminder that our **Junior Ostomy Support Helpline** is there to support them, their parents and carers. Thank you for inviting us, we had a great time!
- ◆ Just before Christmas we met with the **Urostomy Association** and the **IA** to discuss a number of joint projects for the benefit of patients as part of our close collaborations.
- ◆ Finally, thank you to **Salts Healthcare** who kindly sponsored our recent volunteer refresher training session at their Academy in the Midlands.

Three Months Down the Line



You may remember on the Readers' Writes page in the last issue of *Tidings* we published a letter from Janet about "Horrid Henry", her seven week old stoma. We asked Janet to tell us more about how it felt in the weeks leading up to surgery and the first three months living with a stoma.

I am 69 years old, live on my own and am a retired dental receptionist. I have two sons, both married. One lives in Hong Kong and one in Manchester and my son in Manchester has two young daughters. I help with sailing for people with disabilities and often look after dogs when their owners go away.

In October 2015, I was about to go to Hong Kong when I developed a "gurgly tummy" and thought maybe it was irritable bowel syndrome (IBS) and would go to the doctor on my return. While away I wondered when I was due a bowel cancer test. I don't really know why as I had no symptoms apart from a "gurgly tummy". A few days after returning a test came through. I sent it off (as I always have done). It came back abnormal, so I did

another one. Also abnormal. Alarm bells started to ring. A colonoscopy in December 2015, then MRI and CT scans in January 2016.

At the end of January 2016 it was confirmed. I had bowel cancer. The tumour was small, curable and hadn't spread. It was, however, in an awkward place. There were tears of disbelief, shock, anger and fear. Also, "why me?" I had kept myself fit and had a healthy diet.

My treatment was to be five weeks of radiotherapy and chemotherapy, in pill form so I would not lose my hair. Then a colostomy and I would never go to the toilet again. Not knowing anything about stomas, I thought I would be very constipated!

Then came the daunting process of telling people. It was very difficult to tell my sons as they had lost their father to prostate cancer in September 2015. Everyone was brilliant – offering loads of help and support. Take whatever people offer – you will need it.

In March 2016, instead of going to South Africa as planned, I spent my days having treatment. This left me tired and sore. It was especially uncomfortable and difficult to sit down. The radiotherapy and chemotherapy finished on Good Friday 2016.

There were a few weeks' respite before my operation which was scheduled for May 2016. Although told the treatment had worked, I still needed the surgery. I had been clutching at straws, thinking maybe the colostomy wouldn't happen. During those few weeks I kept myself busy; spring cleaned the house and went out as much as possible, even managing three days in Spain. As the date for my operation drew nearer I even started counting how many days I would have a bottom left. I did not want to think about the operation, and could not imagine what my tummy and bottom would be like afterwards. The operation took place on a Thursday in May and I came home the following Monday with my new friend for life (Horrible Henry), that is what I named my stoma. I was disappointed to find it was still very uncomfortable and difficult to sit down after my surgery.

My next task was learning how to change bags. What type to use? Closed or drainable? One piece or two piece? At the moment I use closed flushable and hope to start irrigation soon. Another challenge was to consider a support garment for when I exercise or do any heavy work (after convalescing) to help prevent a hernia.

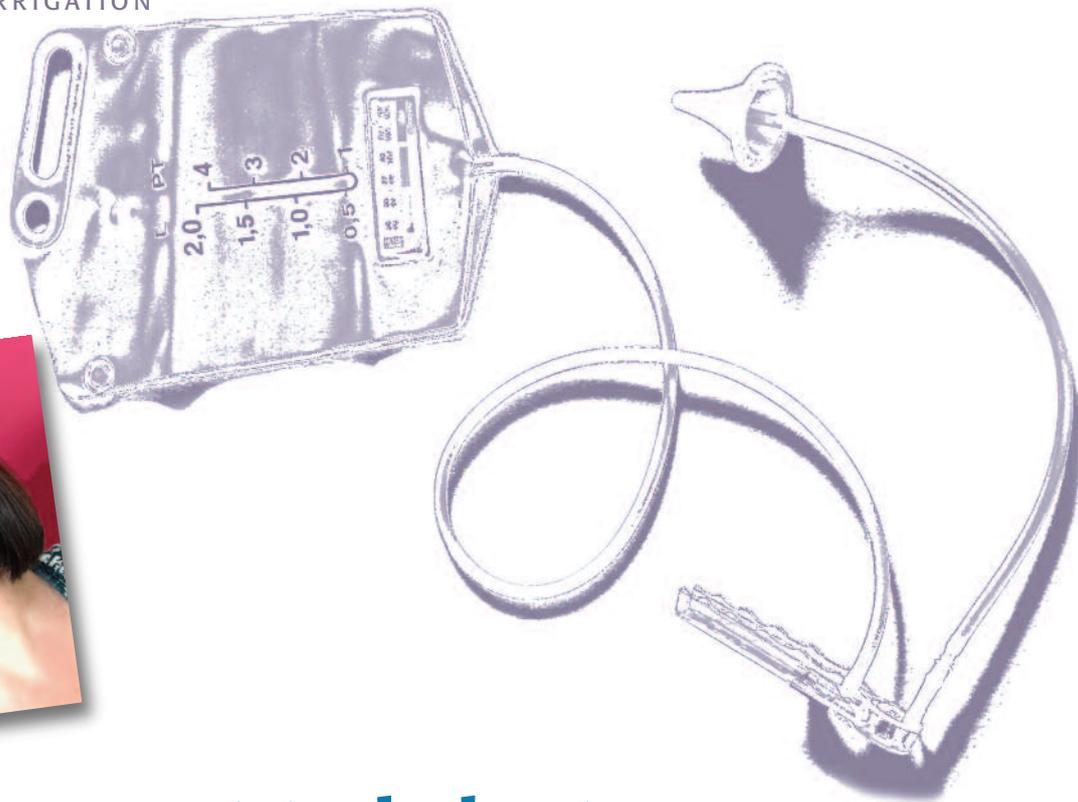
All these months everybody continued to give me help and support. As I said, take any you are offered.

When "Horrible Henry" behaves we get on reasonably well. If he misbehaves, then my bathroom suffers, in more ways than one. I haven't yet punched a hole in the wall. In the beginning, Wednesdays always seemed to be a bad day and I called them "Wobbly Wednesdays". I have a mentor from the **Colostomy Association** who rings me on a Wednesday and we chat about various subjects (not all to do with Horrid Henry) and I have found these chats very reassuring.

In the middle of June 2016 I was told I was cancer free. This time tears of joy.

Three months down the line life has changed. Some things take longer – remembering to take supplies when I go out. I am back at the gym wearing my support belt and beginning to get back to doing things for myself. Maybe in a few more months when I am still here, cancer free thanks to Horrible Henry, he might become "Nice Henry".

I would like to thank the NHS staff for their prompt diagnosis and treatment and ongoing support.



To irrigate or not to irrigate... That is the question

As regular readers know, I am a keen irrigator. For me it was a choice, a way to manage my colostomy which suits me, but I am very aware that some people are not able to irrigate. There are also others who don't want to try. I like to think that if you are able to irrigate and would like to try we need to be here to help, with information and support. But if you are happy with your stoma and have no desire to try irrigation that is also fine and there should be no pressure on you to give it a go.

I know irrigators are sometimes criticised because we spend a lot of time saying how it has changed our lives. For those who can't irrigate this must be frustrating, especially if you are having issues which irrigation may solve yet you are not a suitable candidate. Irrigation is not an exact science as I've said many times before, so hints and tips can make a huge difference to someone who is struggling to get the hang of it. This is why we are keen to have a regular slot in *Tidings* for irrigation so if you are someone who can't irrigate I hope this goes some way towards explaining why we continue to include the page.

In this edition I wanted to look at why people irrigate, what it means to them and why others choose not to. I approached the **Colostomy Association** Facebook group with the question and I was absolutely inundated with responses. Names are only used where I have been given permission:

- "It took me years to decide to irrigate – I thought I managed quite well without, but eventually got fed up with looking for public loos and dreading long journeys and days out. The final decision came when I found out I was going to be a grandparent, so with lots of encouragement from friends I took the plunge – then wished I hadn't wasted so much time. It has been life changing, even with the odd hiccup along the way!"
Sally
- "Never really had many problems with my bags so never really considered irrigating. I have to be honest that the thought of it doesn't appeal to me."
- "I read about irrigation in *Tidings* before I had my 'Barbie bum op' and decided there and then that it was for me. My stoma nurse agreed and four months

after my op she showed me what to do. I have now been irrigating for ten years and would have to be dragged kicking and screaming back to bags!"

Wendy

- "I haven't tried it because the thought of putting something in there freaks me out."
- "Irrigation changed my life and gave me control again. I was no longer at the mercy of my poo. I was back in control, irrigating once a day with no output until I irrigated again the next morning. Best thing ever. I recommend it for anyone medically cleared to do so. Amazing!"
Amy
- "Not for me I'm afraid. I don't like my stoma and don't want to give it the attention of irrigation."
- "Being able to irrigate was crucial for me, to gain a bit more control so I could

(95% of the time) feel confident about my work and when socialising with family and friends. Most of the time I can forget my stoma and enjoy life as much as I did pre op."

Bill

- "I tried irrigating and it was successful but it was not practical to tie up the bathroom for that length of time in a household of five people. Had to stop."
- "...My main reason for changing to a colostomy from an ileostomy was so I could irrigate. I have two young children and being able to irrigate gives me the freedom to go to the park all day and not need to rely on a toilet being there...and to be able to sit in meetings at work without the worry of leaks or pancaking. Irrigation has given the freedom and flexibility to live my life how I want to. The thought of not being able to irrigate fills me with dread and I'm willing to get up a bit earlier each day to irrigate as the pros far outweigh the cons for me."
- "I 'go' in the mornings as in my pre colostomy days and usually nothing more during the rest of the day. I just get up an hour earlier if I have to go out early. Thankfully, I do not see the need to irrigate."

● "Even at 81 years, thank God, I still have a full and wonderful life. I irrigate every other day. Of course, being retired, time is my own but to anyone having doubts I say TRY IT. I did. The best thing I ever did."

Shirley

● "I have tried irrigation three times, the longest for three weeks. It never worked for me and I am very sad about that! Very envious of those who do."

Jane

● "I had been asked by my stoma nurse and read a lot on here about irrigation. I was resistant to the idea...After about six months procrastinating, I decided to give it a go and haven't looked back since. In my view, it represents the gold standard of colostomy management."

Steve

● "I keep giving irrigation a fleeting thought, but at the moment I have a very well behaved stoma. It is also very tiny and my stoma nurse said it wouldn't be suitable for irrigation. I understand that irrigation takes a bit of time. I'm not really a morning person and would rather spend longer waking up and getting ready for the day ahead at my own pace...changing my bag takes only a minute or two."

● "...I wasn't sleeping or coping too well, my stoma was working anytime during day and night. It affected my confidence, I wouldn't leave the house for long. I'd read about irrigation in *Tidings* but didn't think I could use this method until a new young stoma nurse came to see me and she happened to mention it and thought It would help me mentally with lots of issues I was having with self confidence as well as my sore skin. It gave me back my life, I started swimming again and going out with friends for lunch etc as I was able to forget I had a colostomy. I have a hernia now but I'm still irrigating though it does take longer."

Shirley

I would like to thank everyone who took the time to reply to my question and I'm sorry I couldn't use them all. We had a good range of views, more from a pro point of view but I suspect that's inevitable as people who use the method may be more likely to respond. Lots to think about, and a few queries I'd be happy to follow up about the practical side of irrigation. Irrigation, for those who are able to try, is a very personal choice, one that many take up and love but it's also not for everyone.

Sarah Squire

sarah.squire@colostomyassociation.org.uk

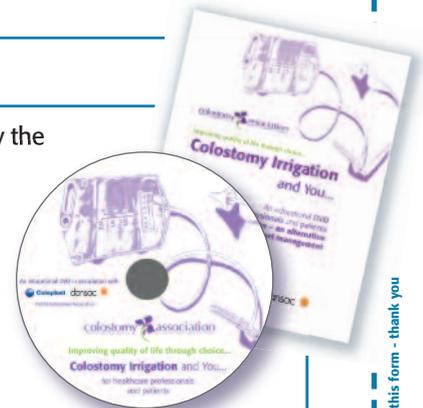
Colostomy Irrigation and You DVD

Order Form Colostomy Irrigation and You (Patients)

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

To obtain your single copy of *Colostomy Irrigation and You* at the special introductory price of £4.99 (incl postage and packing) simply fill in your details below and return it with your cheque made payable to the **CA Ltd**, to:

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Aura Flushable is the next generation of stoma pouch in our flushable range – the only flushable range in the world. The inner liner of *Aura Flushable* can be flushed either with or without the flange as both are fully biodegradable. As well as reliable, convenient and flexible disposal, *Aura Flushable* offers the comfort of medical grade Manuka honey, which may help promote healthy skin around the stoma.

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Aura[®]
with Manuka honey

CliniMed[®]

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PICTURE THIS

Calling all lens men and women

Andy Warhol once said that in the future everyone would be famous for 15 minutes. Well at the **Colostomy Association** we're going one better and offering successful entries for our 2018 Calendar competition a whole month of fame! So if you want your work of photographic art adorning the walls of homes up and down the country, then prepare to 'grip and click'.

Our theme for the year is 'travel'. Please feel free to interpret this broadly. Pictures of stunning landscapes and exotic locations will be welcome, but maybe you can come up with an unusual

angle? The idea is to show that having a stoma doesn't prevent you enjoying life to the full. All photographs will be judged anonymously and the best 12 will be shortlisted for inclusion in our 2018 Calendar.

To enter the competition all you need to do is set your camera to the highest quality setting (so that your photograph/s will be suitable if enlarged to A4 size) and then e-mail them to arvind.anand@colostomyassociation.org.uk no later than 30 April 2017. Arvind hopes to hear from all would-be stars soon!

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The building blocks of our **home delivery service** is to put you first. We deliver all brands of stoma, continence and accessory products discreetly to your door and with text message delivery updates we work hard to ensure our service supports you.

We offer personalised pouch cutting and a wide choice of complimentary items. Our friendly customer service team is available Monday to Friday, 8am – 9pm and has over 20 years experience in providing expert product advice from all manufacturers.

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or call us on

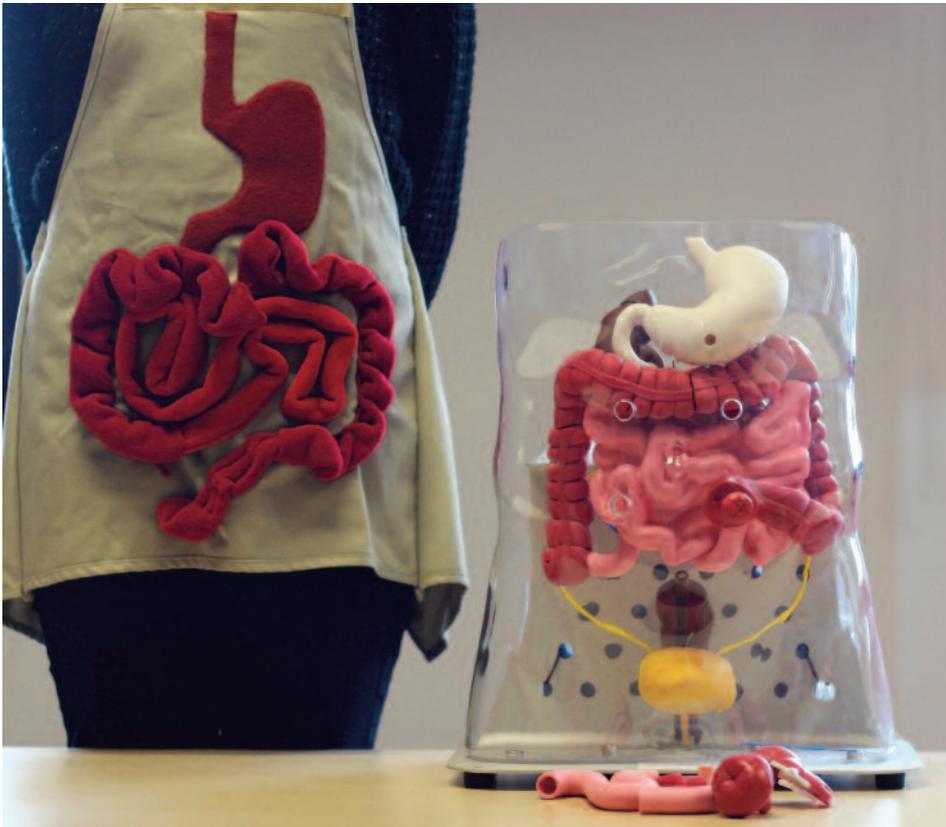
0800 585 125

Association of Stoma Care Nurses (ASCN) Conference

Last year's annual ASCN conference was held in Bournemouth in late September 2016 and several volunteers plus our General Manager went along to represent us on our stand. It was another huge success and our attendance was kindly sponsored by Coloplast for the second year in a row.

Our presence is always invaluable in terms of chatting with hundreds of stoma care nurses, promoting our free services and resources, giving out leaflets, explaining how our volunteers can support patients locally, generating leads for interesting articles, learning about new developments in stoma care, displaying large posters giving information on various **Colostomy Association** initiatives and networking with representatives from the stoma industry and other associated charities.

This event was also the ideal opportunity to demonstrate first hand our interactive anatomy apron and three dimensional Otto Ostomate, which can both be purchased from our online shop or by calling the office. These are ideal teaching aids for nurses and other healthcare professionals.



This national event is attended by more than 450 nurses who travel from all corners of the UK (and some from further afield). During the conference nurses have the opportunity to attend topic talks to broaden their knowledge, learn about the latest research, digest posters on a variety of stoma care subjects, view all the latest stoma care products from a wide range of companies and pick up resources which are beneficial to their patients.

The ASCN conference seemed busier than ever, with our stand being crowded at times – some three people deep! It was certainly worthwhile and there is always a long list of actions after each ASCN conference. These include despatching large quantities of literature to hospitals, registering new nurses on our database, setting up meetings with key contacts, liaising with potential contributors to *Tidings* magazine and arranging dates for workshops.

Our thanks go to Coloplast for sponsoring our attendance again as their financial support is very much appreciated and to CliniMed who invited us out for an evening meal with the IA and Urostomy Association.



New Volunteers Needed

Would you like to:

- join our highly valued team of trained volunteers?
- become a telephone helpline operator and man our 24 hour helpline?
- represent us at hospital or manufacturer open days in your area?
- offer telephone support to somebody who is experiencing similar issues to those you've faced yourself?
- give reassurance to people local to you?
- build relationships with your stoma care nurse?



We urgently need more volunteers who can help us provide support for thousands of people each year, both pre and post op because we can offer them real-life support through our own experience. Most specifically, we desperately need people living in Scotland and Wales due to the geographical spread of each of these countries, and other specific areas such as Cumbria, Lancashire, Yorkshire, Greater Manchester, Lincolnshire and Cornwall to name just a few.

Training courses are offered to those who pass the initial vetting process and ongoing refresher training sessions also take place.

If you have had your stoma for at least one year, are good at listening, have a genuine interest in helping others and possess excellent inter-personal skills, we'd like to hear from you.

Our books are now open so please contact volunteer@colostomyassociation.org.uk for more information and an application form.

We hope to hear from you soon!



One year on...

Stoma Aid launched a year ago and since then has provided invaluable stoma resources to thousands of people in developing countries. As we celebrate Stoma Aid's first birthday, it's a good time to look back on what's been achieved so far and outline our hopes for helping more people in the future.



We all know how difficult it would be for us to cope physically and emotionally if we did not have our own supplies. This makes empathising with people in developing countries easy. The thought of using a tin can, crisp packet or carrier bag tied with a piece of string is not a pleasant one. It is perhaps because of this that the last 12 months have been so amazingly successful! Donations of unwanted supplies have been pouring in from individuals, hospitals and support groups. Manufacturers have sent us end of line supplies. Several support groups have even been kind enough to gather unwanted items from their members and ferry these to our Bolton warehouse in person.

In October 2016, Ian Jackson, Trustee, and Martin Robbins, **Colostomy Association**

Volunteer and representative of the Coventry Stoma Support Group, visited the warehouse to drop off unneeded supplies. Ian and Martin were able to see first-hand the racks of shelves bulging with incoming parcels and the huge quantities of items that are hand-sorted every month. The operation is overseen by **Colostomy Association** Trustee, Frank Healy (pictured left with Crisi Taylor), who has worked tirelessly on a voluntary basis all year to ensure the initiative's success.

At the moment, our main outlet is through Hospices of Hope. From their hospice in Chisnau, Moldova, they distribute the supplies we send them. This ongoing relationship helps over 1,000 people each month, many of whom travel from remote areas to collect their stoma supplies. Additionally, through the kind support of their embassy in London, we have been able to send several Stoma Aid shipments to the Kosovo Ostomy Group. Unfortunately, the latter are now having to fund the high costs of transport and import tax, but we are hoping that this line of distribution will continue in the future. Meanwhile, individuals in Mauritius, Pakistan, Ethiopia, Uganda (including a young baby) and Kenya have also benefited from aid parcels collected by a relative visiting the UK or via other legitimate contacts.

Here's a quick summary of what's been achieved in our first year (as at 31 October 2016):

| Country | Quantity of items distributed |
|--------------|---|
| Moldova | 138,570 stoma bags 40,000 further stoma bags estimated for November/December |
| Kosovo | 2,780 stoma bags |
| Mauritius | 200 stoma bags |
| Pakistan | 200 stoma bags |
| Uganda | 410 stoma bags |
| Kenya | 500 stoma bags |
| Ethiopia | 400 stoma bags |
| TOTAL | 182,080 |

We plan to help additional people around the world in the years to come, handling each enquiry on a case by case basis. Links to other contacts are in the pipeline so watch this space and help us keep the initiative going into the future as Stoma Aid makes a huge difference to people's lives.

Feedback from beneficiaries has included:

- ❖ A man who wept on receipt of a parcel of bags saying he could now go to his daughter's wedding.
- ❖ A man who said he had been able to move back into the house, after sleeping rough in the barn as his family could not bear the smell from his make-shift receptacle.
- ❖ A lady said she had been able to find work for the first time since her stoma surgery now that she could collect her body's waste in a stoma bag.

It is only as a result of the generosity of our volunteers and supporters and with the help of manufacturers that we can continue this aid. Our special thanks go to everyone who has donated their surplus items due to reversal, change of stoma shape/size, allergic reaction or sadly loss of a loved one. These donations make a very real difference for the cost of a £5-£10 parcel. Look out for further life stories in future editions of the magazine as we progress into our second exciting year of running Stoma Aid. ■

How you can make a difference

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

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

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

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

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

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

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

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

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

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

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

COLOSTOMY DAY 2016

FIGHT THE POO TABOO

Colostomy Day took place on Saturday 1 October 2016 and was hugely successful. We would like to say a special thank you to everyone who took part.

From as far north as Scotland to as far south as the Channel Islands, people across the UK either made some noise or stayed silent and helped to fight the poo taboo.

So many people took part that we simply can't feature everyone in this edition. Here's just a few examples...

In Orkney, **Lloyd Wainwright** spoke on BBC Radio Orkney and ran an information stand in a local pharmacy.

Louise Skelding made and sold awareness raising bracelets.

and **Ian Jackson** protested in Norwich City Centre.

Caroline Bramwell held a swimming session in Sidmouth.

Jackie Robinson took part in a photo shoot.

Shell Lawes and the Sheppy Ostomy group organised a swimming session.

Moira Hammond spoke to the Stoke Sentinel.

Jersey Ostomy Society held a cake sale.

Caroline Emeny





Erewhash Indoor Bowls Club held a bowls game.

Meanwhile companies in the stoma industry also did their part: **Welland** had a cap competition and took part in the Warrior Run, **ConvaTec** organised walks for awareness, **SecuriCare** and **CliniMed** had a fancy dress day.

In the office, staff and volunteers dressed up in loud clothing and manned a stand outside Enterprise House to raise awareness among the general public.

On social media many of you were sharing your stories and photos of your tummies. We were tweeting

myths and sharing statistics from our 2016 quality of life survey as well as retweeting your own comments. We made so much noise that #colostomyday was trending on Twitter on Saturday morning! (For those not in the know, this refers to a hashtag-driven topic that is immediately popular at a particular time.)

Here are some photos of the events and activities that took place, but others will follow nearer the time of our 2017 Colostomy Day so look out for further details and keep the date of Saturday 7 October 2017 firmly in your diary...

Thank you again everyone for making Colostomy Day 2016 such a huge success.



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Stoma Friendly Society

Our campaign continues to champion your rights and to raise public awareness generally. We are actively campaigning to ensure that facilities across the UK meet the needs of people who have a stoma. This involves working with businesses, public bodies and policymakers to improve toilet facilities and to reduce the discrimination many people face when using accessible toilets (30% of people according to our survey last spring).

What's been happening

New 'Stoma Friendly' Toilet Stickers

We are delighted to announce that our new toilet stickers have arrived (see main image above). The stickers help raise awareness with the general public that not all disabilities are visible and that they should not challenge those using the accessible toilet.

We are already working with several large organisations across the UK who will display our stickers; these currently include shopping centres, tourist attractions and educational establishments. Over the coming year we will be developing further relationships with well-known companies in order to make a real impact.

Your support group can help us with our campaign by encouraging local organisations to become involved. Support groups are already campaigning on our behalf in Coventry, Cornwall, Glasgow, Hampshire and Salisbury. If your support group would like to get involved

please contact Clare Matthews, our Marketing Officer, to discuss further. Email: clare.matthews@colostomyassociation.org.uk



Last year, one of our Trustees, Peter Martin (pictured above, right) visited Lord's Cricket Ground to discuss how they could improve their accessible toilets so that they fit our requirements. The meeting was incredibly successful and we should have more news on this in the next edition of *Tidings*.

Meanwhile, Crohns and Colitis UK are campaigning for better signage on accessible toilet doors. Asda have already committed to changing the signage on their doors to read 'not every disability is visible' (see image in next column) and Crohns and Colitis UK are meeting with all the large supermarkets to encourage them to make similar changes. We had a very successful meeting with Crohns and Colitis UK in the autumn and had hoped to be involved in these discussions. However, the Charity has agreed to mention Stoma Friendly toilets when they meet with the supermarkets and



we look forward to updating you on the outcome. This will all greatly help to improve the public's overall awareness and should help to reduce the number of people being challenged when they use an accessible toilet.



Additionally, we voiced our concern over the closure of the public toilets in Pangbourne, Berkshire. Following on from a community meeting, there have been enough pledges of financial donations and volunteer support from the village and the surrounding areas to start the process of setting up a charity, with the intention of re-opening the toilets as quickly as possible. If you know of any local public toilets that are under threat of closure, do let us know.



Finally, we're delighted to announce that we're now a member of the 'PTUK Consortium'. This organisation was set up by Public Toilets UK (PTUK), Crohn's & Colitis UK and The Centre for Accessible Environments and aims to improve and increase toilet access for all. We will be working with the consortium on various campaigns and proposals. Find out more in the next edition of *Tidings*. ■

Travelling abroad this year?

Here are a few reminders about what to expect at the airport.

More tips from seasoned travellers who happen to have a stoma will be published in the Spring issue of *Tidings*

Hand luggage restrictions at UK airports

There are restrictions on the amount of liquids you can take in your hand luggage when boarding a plane in the UK. If possible, pack liquids in your hold baggage (luggage that you check in).

Liquids include all drinks, liquid or semi-liquid foods, cosmetics and toiletries, contact lens solutions etc. and gels.

For ostomates such items as **adhesive removal spray** and **odour neutralizers** are included in these restrictions.

If you do take liquids in your hand luggage:

- currently containers must hold no more than 100ml;
- containers must be in a single, transparent, resealable plastic bag, which holds no more than a litre and measures approximately 20cm x 20cm (you may be

able to get a suitable bag at the airport before you go through security);

- contents must fit comfortably inside the bag so it can be sealed;
- the bag must not be knotted or tied at the top;
- you're limited to one plastic bag per person;
- you must show the bag at the airport security point, usually by placing it separately on the conveyor to go through the X-ray machine.

You are allowed to carry essential medicines of more than 100ml in your hand luggage, but you need supporting documentation from a relevant medical professional (e.g. a letter from your doctor or a copy of your prescription).

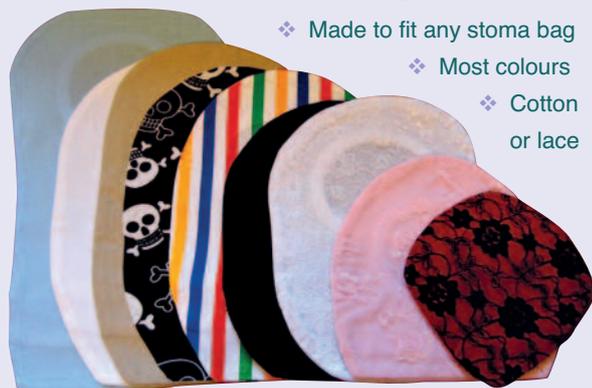
See www.gov.uk/hand-luggage-restrictions for more details.



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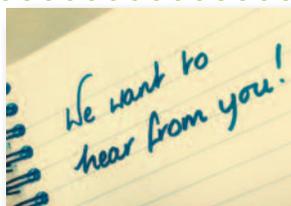
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If you're currently using a flushable pouch and would like to share your story, please call the **CliniMed Careline** on **0800 036 0100** or email flushableadvocacy@clinimed.co.uk

Holidays since my operation



After reading other travel stories in the spring 2016 edition of *Tidings*, Len, aged 77, thought about his own journey since his abdominoperineal resection (APeR) in September 2011. It took nine months for his perineal wound to heal, but after six months he plucked up the courage to have a holiday. Len explains how he began by visiting familiar places in the UK before venturing further afield.

For my first weekend away I chose a small country inn in Norfolk. At dinner on the first night I ordered garlic mushrooms. I love them but I found out they don't love me anymore. Within 20 minutes I was dashing back to my room to change my bag. Early next morning I woke to find my bag had started to leak, but luckily my wife had bought a big towel from home and I had wrapped this around me. When I returned home, I felt a bit deflated by what had happened and spoke to my stoma nurse. She listened to my tale and gave me words of encouragement.

For many years, we had been visiting The Yorkshire Dales and Pembrokeshire staying in guest houses, and had become great friends of the proprietors. They were aware of my operation so I thought that a trip to both these places would be a much less stressful way of getting used to coping with a stoma while away from home. This worked fine; my friends went out of their way to help me, and my wife and I were also able to get back into our favourite pastime of walking.

We do like to travel but I could not pluck up enough courage to try a trip abroad so in 2013 we again went to the Dales and Pembrokeshire. We also booked a couple of holidays at the Warner Adult Hotels in England. I told them in advance that I had a stoma and they supplied me with clinical waste bags.

I was still wary about going abroad but thanks to the articles in *Tidings* magazine I began to think more about trips further afield. Then in 2014 I had an email from Titan Holidays showing an 11 day cruise on a small ship along the Istrian peninsula and visiting Croatia's islands. The ship is small and only takes about 32 people. I telephoned Titan and told them about my stoma. They checked with the ship's owners in case there was a problem about waste disposal but they cleared it as OK for me to go.

The holiday was so relaxing. The crew were very good and the other passengers very sociable. We sailed around the islands and best of all we dropped anchor in small bays and swam off the back of the boat. This was one of the highlights of my holiday as I had not been swimming since my operation. At this stage I did not have high-waisted swimwear so the stoma bag did show above my swimming trunks. One lady told me she used to be a Macmillan nurse and congratulated me on going swimming. This boosted my confidence. On returning home I purchased a pair of high-waisted swimming trunks and started swimming again at my local pool.

This trip to Croatia helped me enormously. It was so good that in 2015 we did a trip around another part of Croatia on a different boat but with the same company. Again, we had a great time. As Mary said in the spring 2016 issue of *Tidings*, cruising is so easy for ostomates.

I am now in my fifth year of remission and looking back I realise how far I have come since my operation in September 2011. Last year, we went cruising again on a small ship with the same company but this time to Dubrovnik and the Dalmatian Islands.

I am not sure I could manage holidays to South Africa, Australia or similar but I am certainly enjoying life. To anybody still contemplating going away for the first time I would say: Relax, do a bit of planning, start gradually and go to familiar places.

Len Faulkner

It is not necessary to inform a hotel that you have a stoma as it is acceptable to double wrap used bags and dispose of them in the bin in the bathroom. Another alternative is to use flushable bags that have an inner liner which can be flushed down the toilet. If you haven't used them before it is advisable to trial flushable bags at home before you go on holiday, just to check they are suitable for you.

But remember, flushable bags cannot be disposed of in systems with small bore pipe-work e.g. in countries such as Greece or on cruise ships.

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Win up to £25,000 with Unity

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Junior Ostomy Support Helpline (JOSH)

The Junior Ostomy Support Helpline for parents and carers of children with bowel and bladder dysfunctions...

Neale Griffiths, JOSH helpliner, kindly volunteered at the annual Association of Stoma Care Nurses (ASCN) conference (see page 26) this year to promote JOSH. Neale was able to publicise JOSH with nurses and stoma companies alike so that more parents and carers will benefit from this vital resource.

Neale chatted with company representatives who distribute paediatric supplies and it is hoped that some manufacturers will now include JOSH leaflets with each paediatric order so that our support can be offered to more parents and carers. OakMed have already agreed to do so.



As a direct result of attending ASCN, a talk will now be delivered at a forthcoming Paediatric Stoma Nurse Group (PSNG) meeting so look out for an update in a future edition of *Tidings*.

Neale also promoted the new JOSH snow leopard to nurses so that the soft toy can be used to engage directly with children of all ages who feel isolated and alone. The JOSH snow leopard has been produced courtesy of grant funding from a variety of resources and it will very much help to raise awareness of the free helpline.

Special JOSH packs have been sent to paediatric stoma care nurses at a long list of children's hospitals across the UK. The cuddly snow leopard will be given to children pre- or post-stoma surgery as a constant reminder to parents and carers that support is only a phone call away, particularly when they are at a low ebb or feel nobody else can relate to their own situation. ■

JOSH now has its very own Twitter account so if you'd like to keep abreast of JOSH developments via social media, please follow us at: <https://twitter.com/joshhelpline>





New Innovation from CUI Wear

Welcome the new “Adjustable Hole Belt”

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

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The **breakaway** Foundation

By the time that you read this it will be 2017 and our tenth Birthday year will be over and Breakaway will almost officially be a teenager. Time really does fly, it's two months since our August family weekend, and we've just come back from ASCN in Bournemouth, so all that's left for 2016 is to finalise all our events for 2017 – "all" is a very small word for something that takes up so much time!

Our August weekend saw us meet lots of families that had never been to a **Breakaway** weekend before. One family travelled for five hours on the train with three changes, their suitcases and a toddler in a pushchair to get there. They loved it so much that they are already planning to come again next year. The feeling of relief when you get to sit down and chat with other parents who know how difficult life can be with a child with a bowel or bladder condition really does know no boundaries. The weather gods were very kind to us and apart from some rain on the Saturday afternoon it was lovely and sunny; canoeing is always so much nicer when the sun is beating down on you as you paddle along the canal and river. It also helps you to dry out when you've got soaked in a 'Which boat can splash the other more?' competition (I appeared to come off worst in our boat!)

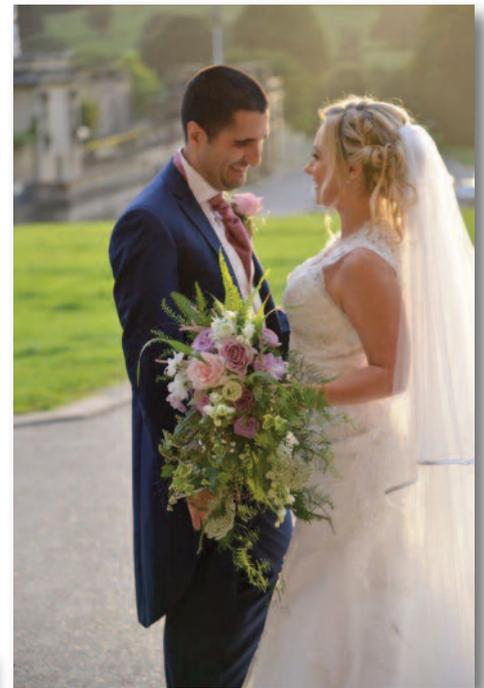
The end of September saw us in Bournemouth for the Association of Stoma Care Nurses (ASCN) annual conference. It was lovely to get chance to talk to so many stoma nurses, and brilliant that so many are now referring their patients to us for help and support. Buttny Bear was with us and, as always, he was very popular. So many of the nurses we spoke to said how wonderful it was to be able to have a stock of Buttny Bears to give out to children undergoing surgery, or to younger children to help explain mum or dad's surgery.

We were delighted that the ASCN committee had chosen **Breakaway** and the Sepsis Trust, to each receive **£750**, the proceeds of a raffle held in memory of Tony Griffiths, one of the Hollister reps, who tragically died in February 2016. Tony was an amazing man, always smiling, always going the extra mile for the patients he spoke to. We were overwhelmed when his family chose us as one of the two charities to receive donations following his funeral.

To honour Tony's memory, we have set up the Tony Griffiths Award, an award that is given annually to the child who has either overcome fear, gone the extra mile, been compassionate to others, or learnt a new skill over the course of a **Breakaway** weekend. Our first recipient was Aaron, one of the **Breakaway** teenagers who went out



Aaron receiving the Tony Griffiths Award



Jenny and her husband, Danny

of his way to encourage the younger children throughout the weekend, making sure that no one was on their own and showing huge compassion. A very worthy winner of the first award.

And finally, back in September one of the first **Breakaway** kids got married! Jenny was a teenager when she had her first stoma after her bowel perforated during a colonoscopy. She came along to **Breakaway** just after she'd had it reversed and was getting used to living with an ileorectal anastomoses. She subsequently went on to have a permanent ileostomy due to Crohn's disease. Jenny has since volunteered with **Breakaway**, and has been a great source of support and encouragement for the **Breakaway** parents, who are always amazed by her resilience and her positive outlook on life. ■

More information about Breakaway Foundation.

Donate online via:
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Write to us or send a donation to:
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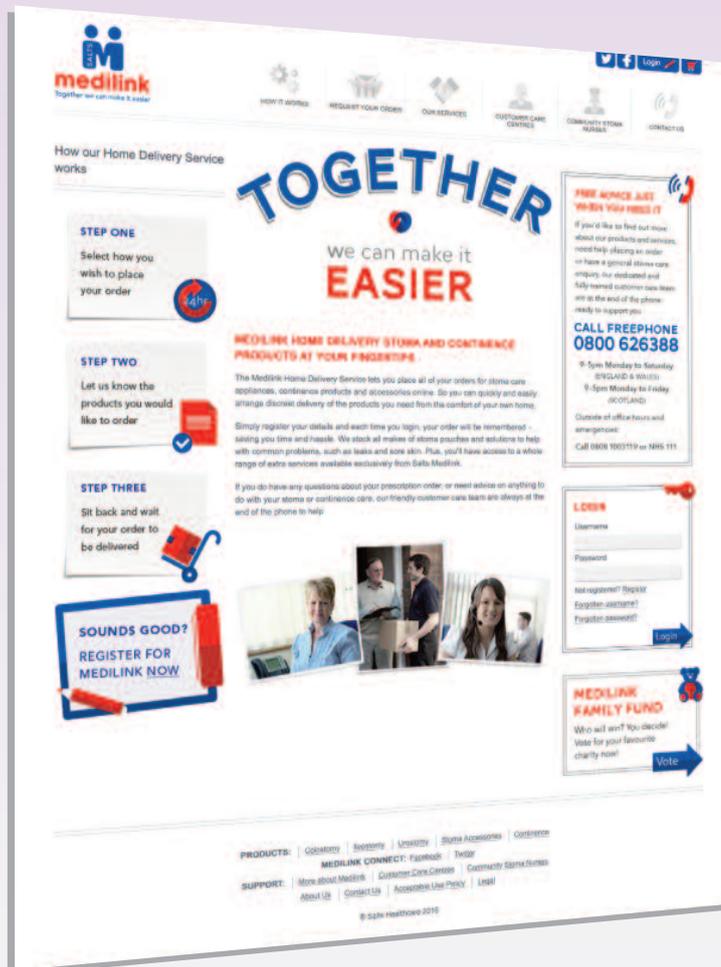
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Colostomy Association Facebook Group

On-line Support

Sarah Squire,
Trustee and Facebook
Admin writes:

I wonder what Gertrude Swithenbank and Frances Goodall would make of Facebook and how our closed group has helped so many people. When they first formed the Colostomy Welfare Group in 1967, electronic computers were just being developed; it was a far cry from the instant accessibility of the internet we have come to expect nowadays. I feel very lucky to have such resources at the touch of a button and remind my kids on a regular basis that I passed my degree with the help of the library rather than the internet – even in the early 90s there was no Google!



Facebook Admins L-R Michael McCaughey, Sarah Squire, Natalie Slow, Steve Clark, Sally Armstrong, Ian Jackson

I really would describe our group as a family. A new member can appear in tatters and within just a few minutes be offered solutions to problems or given a virtual hug. You can almost feel the relief as they post and realise they aren't alone, we have walked a mile in their shoes and understand. We are very careful not to offer medical advice and always refer to a medical professional when appropriate.

Here is an example of how our group members have helped somebody:

A young mum got in touch – her baby had very sore skin and it was the weekend. He was in hospital but ward staff were out of ideas. In a very short time she was directed to a list of remedies we have built up through experience. By the end of the day this little boy had a product secured in place and it wasn't leaking.

Here are just a few of the many quotes about how being in our group has helped members, kindly collated by Ian Jackson, **Colostomy Association** trustee and Facebook Admin:

"I would just like to say hi to you all. I am new to this group, as of yesterday! I had a colostomy six weeks ago today so still in the process of adjusting. I spent a

couple of hours yesterday just reading through posts and replies and I have to say what a lovely supportive, informative and helpful group of people you all are. Although I have a fantastic husband, son, family and friends it is nice to know that this group is here with personal experiences and tips to turn to."

"I've had my stoma a year today! It seems to have gone so quickly, I'm so glad to have found this group and amazing bunch of people! It would have been a lot harder to get through without you all, thank you"

"Would just like to say a massive thank you to everyone who helped me last night when I was having a meltdown. It helped so much to just get it all out of my head and made me feel better as it's not swimming around my head as much today. You all mean so much and thank you again xxxx"

"Summer bring it on, hoping to wear my bikinis this year, this group has given me the confidence to do that."

It's not all problems and solutions on the group though. We appreciate that off topic posts can also help lift someone who is down, make someone smile or laugh (or

groan as is the case with Steve Clark's jokes!). We feel we have a good balance which makes the group a very special place. Our amazing members make the group what it is and I am grateful to all of them for being a part of it.

If you don't use Facebook and would like to join our group it is fairly simple. Use a search engine to find Facebook or type in facebook.com and follow the instructions on the screen to set up a profile. You don't need to use your real name but must use a registered email address as you will need it to verify your account. Facebook will not give the email address to anyone and if you prefer you don't need to have friends, photos or engage with anything other than the group. To find the group, once you have set up your profile type '**Colostomy Association**' into the search box at the top of the Facebook screen. You may see a number of answers, including the **Colostomy Association** Facebook page which is our public page. Choose the group and you will be taken to the group feed. Click on the 'join' tab and an admin will be alerted that you are waiting. One of us will add you as soon as we get chance and once you are a member you will be able to see posts and comments. We look forward to seeing you there!

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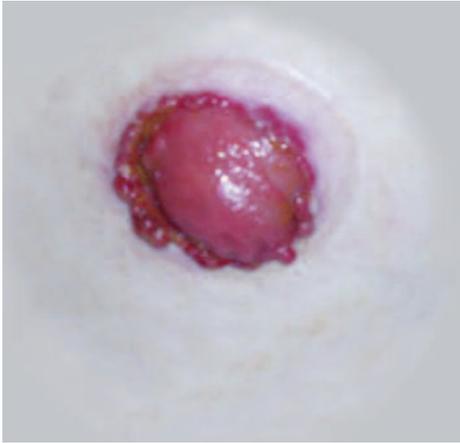


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Colostomy with multiple granulomas

Julie Rust answers your questions about Granulomas

What is a granuloma?

Granulomas are very common and are small areas of over granulation tissue that appear as fleshy protuberances like tiny beads of varying sizes. They occur on the surface of the stoma or more commonly at the muco-cutaneous junction (the join between the bowel and the skin).

What causes a granuloma?

They can be due to inflammation, infection or faecal irritation from the stomal output. Irritation from the ostomy appliance can also be a common cause.

What can we do to prevent granulomas?

Ensure that the hole in the flange/baseplate of your pouch is the right size, so that the edge does not rub against the stoma.

Good pouch changing techniques are an important part of reducing the risk of granuloma formation:

- ❖ Remove the used appliance slowly and gently. Start at the top and support the skin as you go. Use adhesive remover spray/wipes to reduce damage to the skin.
- ❖ Wipe away any faeces with toilet paper then wash the stoma and surrounding skin with warm water and dry the area thoroughly using dry wipes or kitchen roll.
- ❖ When fitting a new appliance, bend the top half away from the body so that you can see to fit the bottom half accurately around the stoma, then press the remainder of the flange into position.

Some people, however, appear to be more susceptible to the formation of granulomas than others.

How do granulomas affect stoma management?

Granulomas can be painful when touched and can bleed very easily particularly

when the skin around the stoma is being cleaned. This bleeding can cause problems with adherence of the ostomy pouch. Good pouch changing technique and a correctly fitting flange/baseplate will help with adhesion. It may, however, be necessary to use additional products such as seals to help the pouch to adhere.

When is it important to consult a stoma care nurse about a granuloma?

It is good practice to seek a review with your stoma care nurse as soon as you notice the granuloma. This is so that a review can correctly identify the lesion as a granuloma and eliminate other medical conditions. This will also allow treatment to remove the granulomas to be started early to try to prevent pouch adhesion problems.

How may a stoma care nurse treat granulomas?

There are several different treatments for granulomas recommended by the Association of Stoma Care Nurses Guidelines 2016 including:

- ❖ Checking if the flange is rubbing against the stoma and if necessary creating a new template which can be used to ensure that the hole in the appliance is cut to the correct size.
- ❖ The use of Orabase protective paste.
- ❖ The use of 75% Silver Nitrate to 'burn' off the granulomas.
- ❖ Application of Haelan Tape.
- ❖ Application of liquid nitrogen.

Some specially trained stoma care nurses and consultants may also use curette and cautery (a special instrument is used to cut out the granuloma and the wound is cauterised or burnt closed).

A review by your stoma care nurse will enable a discussion to occur with regards to the best treatment pathway.

Will granulomas eventually go away without treatment?

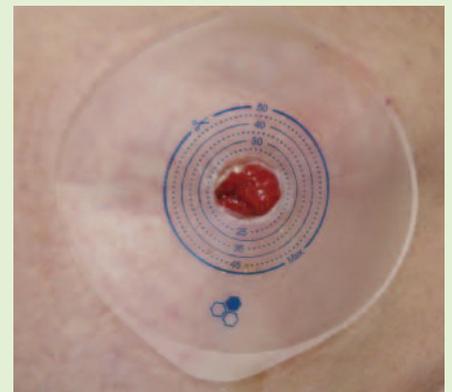
Usually some form of treatment is required, even if it is only the application of Orabase Paste when the granuloma is very small. The earlier the treatment is started the better.

Are they likely to re-occur?

Yes, some people do find that granulomas can re-occur and they should seek a stoma care nurse review as soon as they feel they have re-appeared.

Reader's Tip

If you wear a one-piece pouch use the backing paper/film that protects the adhesive on the flange to check that the hole is the correct size. Hold the backing film around your stoma; it can be difficult to see if you are looking down so it may be helpful to stand in front of a mirror or ask someone else to check for you.



There should be a 1–2mm gap all around to prevent the edges of the hole rubbing on the stoma, whilst still ensuring that the contents of the pouch do not come into contact with the skin.

Dear Nurse

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



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

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

Q: *I have had a colostomy for 10 years after bowel cancer and get on fine with "Bilbo" who is generally very well behaved. In recent months, however, I have started to feel a stinging sensation when I am lying down in bed and he is 'in action'. The pain can best be described as a stinging or burning sensation which comes and goes at the stoma opening. Has this been experienced by others? Can you suggest a cream or something I could put on or up the stoma to ease this nasty stinging? I don't very often notice it when I am upright. It is bearable but irritating when I am trying to get to sleep.*

A: This could be due to a small wound on the stoma or some peristomal skin irritation at the muco-cutaneous junction (the join between the skin and the stoma). As it occurs when you are lying flat it may be that the stoma is 'telescoping' (retracting back below the skin surface) when you recline. The use of Orabase Paste, applied to the surface of the stoma, may help. I would suggest a review by the stoma care nurse who can have a look at the stoma and skin and assess if it is telescoping and also check the stoma size to ensure the template is a good fit. They can then

advise with regards to treatment, including the use of a different pouch such as a convex appliance if the stoma is 'telescoping'.

Q: *I am 71 years old male, height 5ft 9ins (1.75m), weight 12st 11lbs (81kg) and have had an ileostomy for 18 yrs. In my early teens, I was diagnosed with ulcerative colitis which was controlled by changes to my life style and medication until I was in my early fifties when things took a turn for the worse and resulted in an ileostomy. Appreciating that with an ileostomy your body does not have the opportunity to absorb nutrients as normal I was surprised not to be placed on any mineral supplements or similar.*

I have survived pretty well on what I eat. However, over the past few years from time to time I become very anaemic caused by iron deficiency. On one

occasion, I was hospitalised and had blood and iron rich transfusions. I have recently been diagnosed again as anaemic, however, this was corrected by medication.

The problem I have is finding someone to speak to that fully appreciates my situation: Someone that can suggest a diet that is high in iron but takes into account that I have an ileostomy and suggest foods or supplements that can keep my daily need for iron satisfied.

I go away twice a year for five to six weeks and during that time eat my main meal early evening with other friends and colleagues. I am now finding that food is going through me fairly quickly. The very liquid output can prove slightly embarrassing if there is no toilet nearby. I drink very little or no alcohol with my meals.

A: By the time food reaches the end of the small bowel (ileum) it has already been digested and the nutrients absorbed. Therefore, no specific diet sheet is required for people who have an ileostomy; a healthy, well balanced diet is recommended. However, some very fibrous foods such as nuts

and the peel on apples, pears and potatoes are hard to digest and best avoided.

The main advice given to ileostomates is with regards to fluid intake. As the output from an ileostomy tends to be fairly liquid there is a risk of dehydration, especially in hot weather. Oral rehydration solutions can help your body to absorb fluid and salt. They are available over the counter from pharmacies, or electrolyte drinks can be made at home (see recipe below for St Mark's electrolyte mix).

With regards to the anaemia, I am presuming your GP has done investigations or referred you to the hospital to rule out other causes of the anaemia. If not, it may be worth a further medical review to assess the reason for the continued/recurrent anaemia. If no obvious cause is identified a referral to a dietitian may be a good idea as they can provide specific dietary information to try to prevent recurrence of the anaemia. They can also give advice with regards to the types of food to eat to try to regulate the

consistency of the stomal output as can your stoma care nurse.

Starchy foods such as bread, potatoes, pasta, rice, bananas and gelatine containing foods can help to thicken up the ileostomy output. Have you had a look at the IA webpage or contacted them? (See page 55 for details) Like the **Colostomy Association**, IA offer very good support and literature to provide information and can also put you in touch with other patients with the same type of stoma.

I hope this helps and you find a solution to your problems so that you can continue to enjoy your regular activities and holidays.

Electrolyte mix (St Mark's hospital formula)

- 20g (six level 5ml spoonfuls) of Glucose
- 2.5g (one heaped 2.5ml spoonful) of Sodium Bicarbonate (baking soda)
- 3.5g (one level 5ml spoonful) of Sodium Chloride (salt)
- Dissolved in one litre of cold tap water

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

E-mail: editor@colostomyassociation.org.uk

or

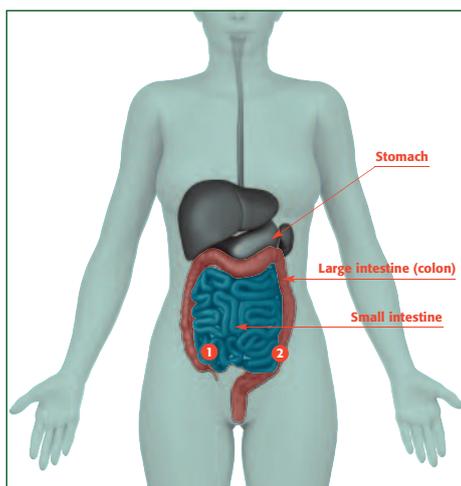
Write to:

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

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

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

What kind of stoma do you have?



- 1** An ileostomy is most commonly formed here at the end of the small intestine, before it joins the large intestine.
- 2** A colostomy may be formed at any point along the large intestine (colon) but most commonly here in the descending or sigmoid colon.

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

Five facts about an ileostomy

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

Normally waste matter continues its journey from the small intestine directly into the large intestine or colon, where salt and water are absorbed. If the colon is brought out through the abdomen to form a stoma (ostomy) this is called a colostomy.

Five facts about a colostomy

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

The above applies in most cases, but there can be exceptions e.g.

Sometimes it may be easier for a surgeon to create a colostomy on the right-hand side.

The output from some colostomies may be fairly liquid particularly if only a small amount of colon remains.



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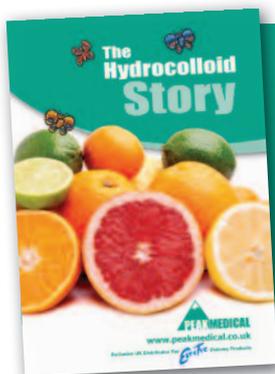


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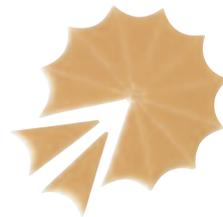
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Readers' writes

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

Rosemary Brierley

Dear Readers

When one takes a holiday, we are often surprised by the things we learn about other people.

I am 73 years old and have just returned to Spain where I have lived for the last 25 years. This was my first time in the beautiful county of Shropshire where I stayed with some dear friends that I met in Spain more than 20 years ago. I not only saw a new part of the world but got an insight into the secret world of people living with a stoma. I say secret because I understand that some people consider it to be a stigma and are ashamed to tell others about it.

I came across *Tidings* at my friend's house as she has a colostomy. The special feature in this issue was summer holidays, giving hints and tips for travellers with a stoma. Being an inveterate traveller myself I was interested and went straight to this article. To my astonishment I had stepped into the world of the stoma and how people learn to live their lives a new way. I was fascinated and not a little shocked. I had no idea about this subject and the difficulties people with a stoma face when travelling, especially abroad.

Miracles are performed every day for people by this procedure. Thousands of people, including young children, are able to live a normal life and to get back to living their dreams and aspirations. None of this would have been possible for them without this medical intervention.

With this new knowledge, I say to each and every one of you ten out of ten for your amazing achievements. Not only that but I award a Gold Star for the partners and families and friends who support and encourage you every day.

Tidings magazine must be a great help for you to handle everyday life and I have to say I found it a mine of useful information as I am sure you do too.

We non-ostomates need to be better informed through the media of TV, radio, newspapers and magazines etc. in order that we can be more supportive too and remove this imagined stigma.

So ladies, gentlemen and you children too, wear your pouches with pride not shame.

Caroline Riva

Dear Editor

I read a reader's report recently about their having a difficult and painful experience undergoing a colonoscopy via their stoma and wanted to share my experience of this to perhaps reassure others that this is not always the case.

I must admit, the account concerned me a little as I was about to have a similar procedure myself – part of my follow-up regime having had surgery for bowel cancer about a year ago.

I raised the issue with my stoma nurse, who admitted it might be uncomfortable, while my consultant made the point that 'going in' via the stoma was less complicated (and hence less risky) than the traditional route as there were fewer turns to negotiate.

I need not have worried, as the procedure was entirely painless and, I should add, a lot more dignified than the colonoscopy I had before my surgery. The taste of the six pints of laxative preparation I had to take beforehand? Well, that's another story!

Carl Difford

Dear Editor

I've had my colostomy for four years and have been irrigating successfully for over a year. The procedure doesn't cause any great difficulty, and the results are liberating. I still manage to play golf and tennis most weeks and sail with my wife, Beth, whenever we can. Our 30ft sailing boat does have a tiny toilet which presented a few logistical problems initially, demanding invention and compromise. When sailing there is no problem as most modern marinas have excellent accessible loos, although finding a hook high enough for the water container can lead to the need for ingenuity. A piece of string helps here allowing the use of any fittings and hooks.

One morning last summer we woke at anchor in a creek on the Isle of Wight. I got up to make the tea and filled the kettle from one of the bottles in the galley; Beth doesn't like water from the boats tank. I passed her a mug and set up to irrigate. Unfortunately, the water from the hot water tank had cooled to luke-warm overnight so I took some from the kettle to 'top up' the temperature.

I started my normal 20 minute infusion when Beth called out from the front cabin – "Ugh this tea is made with lemonade! Which bottle did you use?" "Ugh," I replied. "I am irrigating with lemonade! I couldn't consult Jo Sica, my community stoma nurse, for advice but I'm happy to report that there have been no long-term effects!

Family comments on Whatsapp included – Don't go Pop! More wind than usual! Try Buck's Fizz next time!

Luis Castillo

CONTINUED ON PAGE 48, COLUMN 1

Readers' writes

CONTINUED FROM PAGE 47, COLUMN 3

Dear Editor

Reply to query on odour (Dear Nurse Page, *Tidings* issue 43).

I have not found any item added to bags that really and truly work to eliminate odour. I have had my ileostomy for some 12 years and, yes, I still struggle, particularly dealing with odour. To alleviate smells, having emptied my drainable bag and while it is still in place, I pour water from a small bottle, in through the opening at the base, swirl it around, empty and repeat, sometimes a couple of times. This gets rid of most surplus matter in the bag. I carry a small bottle of water with me in my handbag and I repeat this function after every emptying. It seems to make a difference as the bag in the main is clean, I then add my 'thickening' sachets. I do also change my bag regularly.

Further to emptying, of course, the next item is the matter in the loo and back to the smell again. I have just purchased some drops available online called Fresh Drops. These I used at the home of my daughter and when I left the bathroom you would not have known I had been in there. The suggestion on the bottle is to drop a spot in the pan before use. I did do this to start with, but then I decided to empty my pouch and then drop a spot in after on the emptied products. I find this better and the perfume is very much a pleasant disinfectant style. I can leave the bathroom at last with some confidence.

The downside is they are a little expensive at £15 for three 100ml bottles; each lasts a couple of weeks. I am now carrying one in my handbag, nothing worse than being in a public loo and dealing with the problem, bad enough at home. Perhaps the drops could be seen as beneficial for us and made available at a better rate.

When I dispose of my discarded bag I shake dustbin deodorising powder into the disposal bag to eliminate odours, before putting it in the bin. When I go away I also take this with me.

Regards
SW

Dear Editor

In the last issue of *Tidings* there was an article on leakage and a request for readers to supply any useful tips. I have this problem and, like the writer, use flange extenders. In fact, I use three so that the flange is covered all the way round.

Initially I used Brava extenders but developed a skin reaction and now find that the Independence Acubond extenders are much better, more flexible and kinder to the skin. The writer says 'not for regular use' but although I dispense with them in the house, I do use them regularly when I go out and wouldn't feel secure without them. I think things are made worse by the fact that I have a parastomal hernia and experience pancaking.

In bad moments, even with three extenders, disasters can happen but I usually get enough warning to deal with things in advance. Thanks for highlighting this issue which can be a major source of anxiety for many people.

Best wishes
Jane F

Editor's Note: The reason that regular use of flange extenders is not recommended is that leakage and pancaking under the flange may remain undetected and lead to sore skin. If you regularly experience leakage it is best to seek advice from a stoma care nurse who will be able to suggest other ways to prevent this occurring, for example a different type of bag. However, as you say, flange extenders can provide extra security when toilet facilities may not be readily available and therefore increase your confidence when away from home.

Dear Editor

I have just received *Tidings* which I always read, especially the letters from people who have stomas. I had my stoma done sometime in April 1967. At the time I was 27 years old, married with two children and my wife was three years younger than me. The surgeon was Professor Jenkins. His registrar had a talk with my wife and said that if I decided not to have the operation I would not be here in six months so I didn't have much choice.

The day before I had the operation Mr Jenkins came to see me, explained what was going to be done and put some crosses on my tummy. The operation took over five hours and in the evening I had to go back to the operating theatre as some of the stitches came undone. To start with I had a couple of problems and I had to stay in hospital for quite a long time.

At that time, I was working as a postman in Horsham, Sussex and had to travel 11 miles from my home in Cranleigh to work every day. I got used to changing my bag, a rubber bag that had to be washed out and reused. I used to go to the hospital to see the stoma nurse every so often. Having a stoma didn't stop me from enjoying my gardening and also going swimming.

One thing I want to ask: no one mentions whether they shave around their stoma. I have found that shaving helps the flanges to stick better. I don't regret that I had the operation now. My late wife looked after me and she had a lot of patience.

Yours sincerely
SP

Dear Editor

I am writing to thank David Cable for his very helpful letter to the editor in the summer 2016 issue of *Tidings* regarding travel insurance.

My husband (81yrs) and I (79yrs) continue to enjoy holidays abroad since I had my colostomy four years ago. Some of the recent quotes we have had for travel insurance have, however, been twice the cost of the holiday itself. After reading David's letter my granddaughter went online to www.insurancewith.com and consequently they were nearly £500 less expensive than the lowest quote we had previously received. My granddaughter found the website to be very user friendly and we were delighted to find affordable insurance.

Thanks again to David and thank you too to *Tidings* which I find extremely informative, enlightening and helpful.

Kind Regards
Margaret Capon

We still get letters from people about the length of time it takes for their stoma supplies to arrive. Readers who have had stomas for many years have written to tell us that the way they have always ordered their supplies, the DIY way (order the prescription yourself, collect it and post it off to the supplier) still works best. In the next issue of *Tidings*, we plan to address this issue and include an article on the different methods of obtaining prescriptions and ordering supplies, to help you decide for yourself which method will be the quickest and easiest for you.

Readers' writes

Dear Editor

I have had my stoma for six and a half years now and had a pretty rough time in hospital. I was in for six weeks; I went in with thrombosis in both legs and while I was in hospital my bowel burst and I ended up with a stoma. I also have a double hernia and my consultant does not want to do a repair operation.

I love clothes and like to be a smart dresser. I have a lot of pancaking and have tried everything. This sometimes lifts the bag off at the top of my stoma and I don't think I need to explain.

I have thrown quite a lot of underwear away so I got this bright idea. If I got bed pads and cut them into nine I could put them between my stoma bag and my briefs. It saves a lot of bother. Other people with stomas who attend the same stoma coffee morning as I do every Friday all thought that it was a brilliant idea.

Kind Regards
MP

Editor's note: You say you have tried everything, but if you haven't seen your stoma care nurse for some time it might be worth contacting her because new products to combat pancaking and leakage are being developed all the time.

The bed pads mentioned above measure 66cm by 53cm and cutting them into nine would give a piece

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

approximately 20cm (8ins) square. For anyone concerned about leakage during the night, using them as described above could provide added security and the reassurance to get a good nights' sleep.

Dear Editor

I read with interest the letter from the 83 year old gentleman in the latest edition of *Tidings*. I am 82 and have had a colostomy for the last 23 years due to rectal cancer. When being prepared for surgery the young stoma nurse said she would have to make a mark on my stomach where the stoma would be.

She was about to make the mark roughly on my waistline. My wife was present and remarked that it should be lower if possible as the proposed position was where my trousers would be belted. This was done and has meant that I have had no problems from clothing for the last 23 years. I wonder whether positioning the stoma in surgery preparation is included to any extent in training. A simple question regarding belt or clothes would avoid future difficulties. I realise that it is not possible in every circumstance.

Yours
Bryan

Editor's Note: These days, stoma care nurses are trained in how to site a stoma, and one of the many factors they take into account when determining the position of the stoma is the style of clothing a patient normally wears. As you say, in an emergency situation siting a stoma prior to surgery may not be possible, due to lack of time or the unavailability of staff during the night.

We want
to hear
from you

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

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

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

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

editor@colostomyassociation.org.uk

or a letter to:

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

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

Readers' replies

In the last issue of *Tidings* we published a letter from David asking if any readers also had problems with stoma function being restricted by the waistbands of shorts and trousers and if anyone had any suggestions of how to solve it.

Graham wrote to say he had a similar problem and also a parastomal hernia, but has found he can purchase underwear which doesn't interfere with his appliance at Marks & Spencer.

Doreen e-mailed to say she has a very large parastomal hernia and all she could wear was men's elastic waist jogging bottoms (ladies' ones aren't elasticated enough and aren't long enough) Not very smart! Then she discovered Damart pull on ladies' (fully elastic waist) polyester trousers with front seam. They come in various colours and four lengths including a longer length (31 inch inside leg). Her husband always comments on how smart they look!

"GOSH"



In West Lothian, Scotland, there is a stoma support group known as GOSH, which is the acronym for GROUP OSTOMY SELF HELP, not to be confused with GREAT ORMOND STREET HOSPITAL!

GOSH was formed in 1994 and has the convenience and privilege of the use of a waiting room in St John's Hospital, Livingston, as a meeting place on the last Wednesday evening of each month. This is an out-patients department, and out of use to patients in the evenings. We even have the use of the wee kitchen, where members can make a cuppa - tea or coffee.

My name is Alistair Moore, and I don't have a stoma. Apart from advancing years, I am relatively healthy, still involved with GOSH, and happy to put something back into the group where my wife, Isobel, received so much help and support.

In late 2004, Isobel required an operation, which involved the formation of a stoma. My wife was fastidious about her body hygiene, and did not look forward to this operation, but fully understood the need for this procedure. In the post operation period, it became clear to both of us that the fitting and changing of the bag was going to be a steep learning curve. On her third and final post operation home visit the stoma nurse for our area suggested that there was a self-help group based somewhere in St. John's Hospital.

This seemed a possibility for assistance. After making enquiries, we discovered GOSH. I was content to drive my wife to St John's for the meetings and nip out for a cup of coffee or take a wander through the nearby shopping centre, but the members virtually insisted that I should stay.

I have to say that I was well pleased that I should be allowed to join the company, since I would be able to get first-hand information on the do's and don'ts in the management of a stoma. We made our first appearance at the GOSH meeting in January 2003, where we were welcomed by the group, and soon became familiar with names and faces. Apart from discussing "How do you do this?" or "Is there a better way to do that?" or "Can your supplier deliver a different type of bag?" there is the social side. Members can enjoy a meal together, especially at Christmas. We also visit suppliers' Open Days, go ten pin bowling, and visit self-help groups in other areas. In the early days of being "kitted out" with a stoma when you need help and advice, a group meeting like GOSH can be most helpful and quick off the ground. We did not miss many meetings until Isobel became very ill, and passed away in January 2012.

The foregoing appears to be nearly all about Alistair and Isobel Moore. But the management of such a group does not happen without some persons to lead the troops.

We have an excellent core of a Chairlady, Lorna, a Secretary, Scott and a Treasurer, Ernie, and everyone chips in as and when required. We must not forget the team who provide tea, coffee, cakes and biscuits at the drop of a hat! If it was not that we have excellent leaders, we would not have GOSH.

We have approached stoma care nurses at local hospitals to ask if, when giving the patient who stays within 15 miles of St John's Hospital their discharge letter, they would be willing to enclose our flier about GOSH. It advises the patient of our presence, and the practical help and advice we can give without crossing the medical line. The flier also gives details of when we meet and the activities of the club, with the contact phone numbers of two of our members.

If you are reading this wee story, and reside within travelling distance of St. John's Hospital in Livingston, and would like more details, please get in touch with Scott on 07502 163 644 or Alistair on 01506 822695

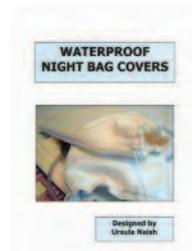
Alistair G-H Moore



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

Events at Local Support Groups



The Lady Mayoress of Oswestry, Irene Constable and Carole O'Ryan

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

Colostomy Association Volunteer, Irene Constable, describes how, together with other members of her support group, she organised a local Open Day.

At a support group meeting we were talking about how we could raise funds to pay for a variety of speakers and perhaps subsidise a lunch or an outing. A bit of research revealed that, to the best of anyone's knowledge, although there had been several Open Days in Shrewsbury and Wrexham, there had not been one in Oswestry and so the idea of organising our own Open Day was born.

Shropshire B.O.T.s started life in June 2011 as The Oswestry Stoma Support Group. It was founded by Carole O'Ryan who had just had a colostomy and found that there was no support available in the area. In early 2012, when my husband and I decided to move to Oswestry, I looked in *Tidings* to see if there was a group nearby. Having been a member of the St Alban's Group, I was pleased to find that there was. When we moved, I went to a meeting and found that Carole was in a bad place with arthritic hips; she subsequently had two replacement hips. While she was out of action, she asked me to take over the group.

We now meet on the second Thursday of each month at 2pm in The Memorial Hall, in the centre of Oswestry and, I am pleased to say, we are a thriving group with around 25 regular members.

We began planning the Open Day in February by sending out invitations to 16 manufacturers and distributors. Initially nine came back saying they would love to attend, so we had the makings of an Open Day. In the end, we had 15 tables booked including Macmillan Cancer Support, **Colostomy Association** and B.O.T.s.

Kirsty Middleton from Pelican Healthcare in Cardiff offered to help with the marketing which was incredible. We had never attempted anything like this before and without her help we would have been struggling somewhat. She helped design the invitations and distributed them to those on the Pelican database in the areas we were targeting. The **Colostomy Association** also offered their services to mail out to our supporters in our area. Many thanks, as we would never have been able to reach that many on our own. We had some A5 flyers printed for the event and the stoma care nurses at both Shrewsbury and Wrexham hospitals gave them out at their clinics. We also distributed across the county in doctors' surgeries, chemists, libraries and anywhere else they would be seen. The local newspaper, *Oswestry Advertizer*, printed a write up before the event and afterwards.

On the day volunteers arrived at 8am and we were ready to for the public by 10am. The Lady Mayoress of Oswestry very kindly opened the event for us, giving a really wonderful endorsement of the group.

What a shock! By the time the event ended at 3pm, around 100 people had attended. We were busy all day making tea and coffee and providing refreshments for the exhibitors. Helen Bracey from ConvaTec

Stoma Aid

If you live in or around Oswestry, Shropshire B.O.T.s may be able to collect any unwanted stoma supplies and take them to the Bolton Distribution Centre. Telephone Irene on 01691 238357 to discuss collection.

explained the three types of stoma with the help of her anatomy apron, and this was followed by a talk on parastomal hernias by Alison Roberts, a stoma care nurse from Birmingham. Both presentations were very well received by their audiences.

The feedback forms we received from the public were all very positive and said they would like us to do it again next year. We also received a similar response from the exhibitors who all want to be invited back.

The best bit was being able to send donations to Macmillan and the **Colostomy Association** from the proceeds of the day as well as having a bit left over to spend on speakers and to subsidise a lunch or an outing this year.

KEEP

THURSDAY 12 OCTOBER 2017
FREE FOR THE B.O.T.s
2ND OPEN DAY

Founder of the group, Carole O'Ryan, would like to add:

Without Irene's help we would not be where we are today.

Great work, Irene, and thank you.

Does your local support group have a special event during the summer of 2017?

Our spring issue will go out early in April so if you have:

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

send an e-mail to

editor@colostomyassociation.org.uk

or a letter to:

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

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

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

My Details: Title: _____ Name: _____ Surname: _____
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 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)

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My Details: Title: _____ Name: _____ Surname: _____
 Address: _____

 Postcode: _____
 Telephone (home): _____ Mobile: _____
 Email: _____

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

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 Colostomy Association – with your help – we can change lives!

giftaid it **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.

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

Signature: _____ **Date:** / / 2017

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National Support Organisations

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

IA The Ileostomy and Internal Pouch Support Group

www.iasupport.org
Telephone 0800 0184 724
e-mail info@iasupport.org

UA Urostomy Association

www.urostomyassociation.org.uk
Telephone 01889 563191
e-mail secretary@urostomyassociation.org.uk

Mitrofanoff Support

www.mitrofanoffsupport.org.uk
Telephone 01202 674336
e-mail info@mitrofanoffsupport.org.uk

IOA International Ostomy Association

www.ostomyinternational.org

Junior Ostomy Support Helpline (JOSH)

via the **Colostomy Association** Helpline
0800 328 4257
e-mail cass@colostomyassociation.org.uk

Breakaway Foundation

www.breakawayfoundation.org.uk
Telephone 01283 240253
e-mail info@breakawayfoundation.org.uk

Support Organisations for associated medical conditions

Beating Bowel Cancer UK

www.beatingbowelcancer.org
Telephone 020 8973 0000

Bowel Cancer UK

www.bowelcanceruk.org.uk
Telephone 020 7940 1760
e-mail admin@bowelcanceruk.org.uk

Macmillan Cancer Support

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

Crohn's and Colitis UK

www.crohnsandcolitis.org.uk
Telephone 0300 222 5700
e-mail info@crohnsandcolitis.org.uk

The IBS Network

www.theibsnetwork.org
Telephone 0114 272 3253
e-mail info@theibsnetwork.org



Stoma care nurses from Kettering General Hospital at their Open Day on 19 October 2016

Stoma Care Open Days

Attending a stoma care Open Day is an opportunity to find out about all the ostomy products and services available and also a chance to meet other people who have a stoma, as well as visit the **Colostomy Association**, **IA** and **Urostomy Association** stands.

These events are often organised by stoma care departments. A range of manufacturers and suppliers will be invited to set up a stand to display their products and services.

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

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

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

Open Days in 2017 that head office is aware of at the time of going to press are listed below. An up to date list, including events in your area, can be viewed on the **Colostomy Association** website.

Musgrove Park Hospital Open Day

Somerset County Cricket Club
(Priory Bridge Road Entrance)
Taunton, Somerset TA1 1JT.
13 April 2017 11am – 2.30pm
Stoma care Dept 01823 342 453

Royal United Hospital Open Day

Bath Racecourse & Conference Centre
Lansdown, Bath BA1 9BU
25 April 2017 10am – 2.30pm
Stoma Care Dept 01225 428 331

Bristol Ostomy Self Support Group Open Day

The Radisson Blu Hotel, Broad Quay
Bristol BS1 4BY
3 June 2017 10am – 1pm
Christina Hammond 07773 869 503
or chris@ostomy.org.uk

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Somerset, TA5 1ZA

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

Stoma support groups in your county

Channel Islands

Guernsey

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

Jersey

Jersey Ostomy Society
Fiona Le Ber: 0153 4445 076 or
jerseystomysociety@gmail.com

England

Bedfordshire

Saturday Social Club
Karen Richards: 0123 479 2278

Berkshire

E.B.O.C (East Berkshire Ostomy Club)
Jackie Dudley: 0134 442 6652
Reading Bowel Cancer Support Group
Ted Wingrove 0118 961 8297
or 07974 790 558
W.B.O.C (West Berkshire Ostomy Club)
Jackie Dudley: 0134 442 6652

Bristol

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

Buckinghamshire

High Wycombe Stoma Support Group
Wendy Hetherington: 07717 335 884

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

Cambridgeshire

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

Peterborough Stoma Support Group – Ostomistics

Alan Wright 0135 465 3290 /
0783 666 1102
<http://www.ostomistics.org/>

Cheshire

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

Stockport Support Group

Angela Simpson: 0161 320 9400 /
0800 652 6667

Stoma Support Group

Catherine McIntosh: 0147 753 5071

Warrington Ostomy Support Group

Jane Shaw: 0192 566 2103

Cleveland

Oops Group
Julie Morrisroe/Carol Younger:
0128 728 4113

Co. Durham

Bishop Auckland Stoma Care Group
Betty: 0138 881 4535 or email:
pgill82171@aol.com

Darlington Support Group

Sister Jacqui Atkinson: 01325 743005

Durham Stoma Support Group

Katie: 0191 333 2184

Cornwall

Cornwall & Plymouth Bowel Cancer Support Group

The Chairperson: 01726 828 419
or The Secretary: 01872 241 145,
cbcsinfo@gmail.com or
website www.cornw

Cornwall Ostomy Support

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

Ostomist and Carers Support Group

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

Cumbria

Grange Cancer Support Drop in
Marie: 0153 953 3279

Derbyshire

Diverted Local Stoma Support Group
Diane Manning: 0128 354 1311

Devon

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

Mid Devon Ostomy Support Group

Janice: 07923 975 051
or 01363 776 417 or
jdkelly234@gmail.com

- Dorset**
Colostomy Urostomy Pouch Ileostomy of Dorset – CUPID (Bournemouth)
Beryl Andrews 0120 248 3303
Colostomy Urostomy Pouch Ileostomy of Dorset – CUPID (Poole)
Jenny Pipe: 0120 274 0440
Colostomy, Urostomy, Pouch & Ileostomy of Dorset – CUPID (West Dorset)
Colin Clare – 0130 585 3238
- East Midlands**
Newhall Stoma Support Group
Diana Manning: 0128 354 1311 or Helena: 0793 233 1850
- Essex**
Connect
Lin Hart 0127 950 5273
Mid Essex Stoma Support Group
Paul Foulger: 0124 522 4374, Jeanette Johnson: 0137 651 1862
N.E.S.S (North Essex Stoma Support)
Secretary: Brian Waller: 0120 654 0449
Optimistic Ostomates
Carol Booth: 0170 238 5510 or Angela Taylor: 0170 238 5509
Redbridge Ostomists Club
Stoma Nurses – Chris/Lisa: 020 8970 8321
STEPS
Jackie: 0126 845 1937 or email: stepsessex@gmail.com
- Gloucestershire**
Ladies Big Op Group
Gill Hopkins: 0300 422 4363.
Please Note: For ladies with one or two permanent stomas
Vale Stoma Support Group
jfn.dursley@gmail.com or text 0794 182 7393
- Hampshire**
Solent Ostomates Support Group (New Forest Branch)
Ron Lever 0238 089 3949 / rdlever@sky.com
Solent Ostomates Support Group (S.O.S.)
Carole Summer: 0752 770 7069
Southern Ostomy Group
Caroline or Karen on: 07756 819 291 southernostomygroup@hotmail.com
Wessex Urology Support Group
Adrian Kuczynski: 07910 786 978
- Herefordshire**
Herefordshire Stoma Support Group
Carol Steele 0143 288 0656 or email: carolsteeleglo@gmail.com
- Hertfordshire**
Colonise
Anastasia 0172 776 0981
Stevenage Ostomistics
Judy Colston: 0143 835 4018 / neilcolston@btinternet.com or Alfred: 0176 731 6958
- Isle of Man**
IOM Bowel Cancer Patient and Carer Group
Heather Norman: 07624 480 973
Stoma Support Group
Carole Cringle stoma nurse: 0162 465 0212
- Isle of Wight**
Optimistics
CNS's Andie Coates & Amanda Broadbridge 0198 353 4009
Semi-Colon Club
Tony Crowson on 01983 559 326 or Cancer Clinical Nurse 01983 534 180
- Kent**
Ashford Stoma Support Group
Carole Hobbs: 0130 381 4014 or Margaret Webb 0123 362 8807
Atoms Support Group
Maria Culleton, SCN: 0122 776 9679 or 0782 799 7424
Dartford Ostomy Group Support (DOGS)
Tracey, John or Sue: 0794 897 4350 or dogs-uk@hotmail.com
Dover Stoma Friends Group Support
Julie Bell: 0777 134 5703 or Ros Marshall: 0130 482 2696 or June Golding (Organiser): 0130 482 2696
M.O.G.S (Medway Ostomy Group Support)
Helen Or Tracey: 0777 360 5534
Maidstone Stoma Support Group
Judy/Kirsty: 0162 222 4305
Royal Tunbridge Bowel Cancer Support Group
Bronwen Tetley CNS: 0189 252 6111 x 2287
Sheppey Ostomy Group Support (SOGS)
Shelley 07714 734 194 / sogs-uk@hotmail.com
SWAN Stoma Support Group
Heather: 0771 144 5312
Thanet Stoma Buddies Support Group
Phil (Secretary) 0184 358 7769
- Lancashire**
North Manchester and Bury Stoma Support Group
Julie Meadows (SCN) 0161 720 2815 or 0784 120 6910
Oldham Stoma Support
June Wilde: 0161 312 5538
Phoenix Bowel Cancer Support Group
Sandra and Nicola 01253 291919, www.phoenixgroupbvh.com or eMail: phoenixbvh@aol.com
Trafford Bowel Care
Jackie Carey Secretary: 0161 748 9659, Doreen: 0161 962 7818, John: 0161 748 4655
- Leicestershire**
Kirby Ostomy Support Group.
Colostomy, Ileostomy and Urostomy in Leicestershire
Janet Cooper: 0116 239 2844 / kosg2013@btinternet.com
- Lincolnshire**
Friends East Coast Support Group
Betty: 0120 572 4120, Sheila: 0120 536 4493
Grantham Support Group
Bobbie/Rachel: 0147 646 4822
Sutton Bridge and Long Sutton Ostomy Group
0140 635 1617
- London**
Bowel Cancer Newham
Scyana: 0208 553 5366 scyana@tiscali.co.uk
ESSence (Ealing Stoma Support Group)
Wendy Hetherington: 0771 733 5884
Homerton Hospital Bowel & Stoma Support Group
Angela Davy: 0208 510 5318 or 0208 510 7599
Rectangle – Colorectal Cancer Support Group
Regina Raymond 020 7472 6299
South Woodford Support Group
Nurse Christina and Lisa: 020 8535 6563
St. Thomas' Hospital
CNS: 020 7188 5918
Surrey & South London Bowel Cancer Support Group
Sue Berry: 0173 755 3134 or John Amos: 020 8668 0796
- Merseyside**
I.C.U.P.S
SCN: 0151 604 7399
St Helens Cancer Support Group
Office: 01744 21831, Denys Floyd: 01744 884097 or email: contact@sthelenscancersupportgroup.org
- Middlesex**
Inside Out
Sarah Varma: 020 8235 4110
Bob (chairman): 020 8428 4242
- Norfolk**
Kings Lynn Ostomy Friendship Support Group
For more info please call 01553 775 698 / 01553 674 962 / 01553 768 271
STARS (SToma And Reconstructive Surgery social support group)
Sylvia Hughes 01263 733448 sylvia.ruth.hughes@gmail.com
- Northumberland**
Berwick Ostomy Support Group
Bobbie Minshall: 0771 447 9320
Hexham Ostomy Group
Judith on 0796 792 7286
Northumberland Cancer Support members@northumberlandcancersupportgroup.co.uk
- Nottinghamshire**
North Notts Stoma Support Group
Tore and Nicky Norman: 0177 371 5460
Nottingham QMC Stoma Support Group
Rosemary Brierley: 0115 982 6691
Nottingham Stoma Support
Jenny or Kate: 0115 962 7736/ Mrs B Heath: 0115 966 3073
- Oxfordshire**
Oxfordshire Ostomy Fellowship
Pat Longworth: 0123 552 4163
- Shropshire**
B.O.T.S. (Bums on Tums)
Irene Constable on 0169 123 8357
- Staffordshire**
Outlook
Moira Hammond 0778 840 2195

SUPPORT GROUPS IN YOUR COUNTY

Suffolk

East Suffolk Ostomy Group
Marion Fisher: 0147 331 1204
James Pagett Ostomy Support Group
(Afternoon Meeting)
Vicki Blackwell on 01493 663363
James Pagett Ostomy Support Group
(Evening Meeting)
Sandra Hutchings: 0150 258 5955
West Suffolk & District Stoma Group
Jessica Pitt stoma nurse:
0163 851 5525

Surrey

Epsom and District Stoma Support
Group
Lindsay, Trevor or Sheena:
0137 273 5925
Normandy Colostomy Support Group
Marina Harkins: 01483 233 126
or 07852 554 049 or Jackie Sanders:
jackie-sanders@hotmail.co.uk
or 07815603742
Stoma Support Group
Robin Young: 01428 723 255

Sussex

Brighton & District Support after
Stomas (SAS)
Sylvia Bottomley: 0127 355 4407
Chichester Stoma support Group
The Stoma Care Team 0124 383 1527
The Ostomy Friends Group
Jane Quigley: 0132 341 7400
ext 4552
West Sussex Princess Royal Stoma
Support
Tina Walker: 0144 444 1881 ext 8318

Tyne & Wear

Gateshead Stoma Patient and Carer
Support Group
Stoma Care Nurses: 0191 445 3152 or
email stuart.sutcliffe81@yahoo.com
NHS Molineaux Centre
John Burchell 0191 265 1047
Royal Victoria Infirmary Support
Group
John Burchell 0191 265 1047

Warwickshire

Warwickshire Stoma Support Group
nuneatonstoma@aol.com

West Midlands

Coventry Stoma Support
Martin: 0794 738 5643

Wiltshire

Swindon IA
www.swindon-ia.org.uk
Wessex Stoma Support Group
Michael Slater:
wessex.stoma@yahoo.co.uk
or on 0172 274 1233

Worcestershire

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

Yorkshire

Acorn Ostomy Support Group
Michelle: 0758 069 3155 (After 6:00pm)
Airedale Stoma Support
Sue Hall: 0153 564 6373
Barnsley Bottoms Up Stoma Support
Group

Stoma Nurses 0122 643 2528 or
Celia Utley (Chairman) 0122 628 4262

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

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

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

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

The Hull and East Riding Colostomy
Support Group
Pete Smith: 0798 956 5335 or
Pete Rennard: 0793 951 8642 /
0148 279 3966 or Rosanna Grimsby:
0148 280 1575. www.hercosg.org.uk

Northern Ireland

Co. Antrim

Colostomy Association Volunteers
Northern Ireland
Chris Wright: 0772 071 7771
Mater Hospital
Karen Boyd – Stoma Nurse:
0289 074 1211 Ext 2329
Royal Victoria Hospital – Belfast
Sarah Haughey/Audrey Steele:
0289 024 0503 Ext 3483

Co. Armagh

Craigavon Area Hospital
Clare Young/Lynn Berry/Janice Garvie
0283 861 2721
Daisy Hill Hospital Support Group
Bernie Trainor: 0283 083 5000
Ext 2222

Co. Down

North Down Stoma Support Group
Adrian Ewing on 0785 074 1511
Ulster Hospital
Hazel/Martina: 0289 055 0498

Londonderry

Causeway Support Group
Mary Kane: 0287 034 6264

Scotland

Ayrshire

Ayrshire & Arran Stoma Support Group
Jim Krasewitz: 0129 222 0945
Stoma Care And Recovery (SCAR)
Maggie: 0129 427 1060/ 0781 773 6147
maggie13@sky.com or Rhona:
0129 455 7478

Fife

Fife Ostomy Support Group
Ishbel Barr: 0159 277 2200

Lanarkshire

G66 Support Group
Les Ireland 0141 776 3866

Glasgow Stoma Support group
Chairperson: Morag Sinclair
0141 779 1322 or Jackie McChesney
01505 324 052

Moray

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

Scottish Borders

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

West Lothian

GOSH (West Lothian)
Scott Pattison: 07502 163 644

Wales

Bridgend

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

Carmarthenshire

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

Denbighshire

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

Flintshire

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

Gwent

Blaenau Gwent Self Help
Celia McKelvie: 0187 385 2672 After
6pm
Cwmbran Ostomy Support Group
(COSG)
Philippa Lewis: 01633 791 339 /
07504 713 069

Mid Glamorgan

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

Pembrokeshire

PSA (Pembrokeshire Stoma
Association)
Roy Whitfield 0143 776 0701

Powys

The Bracken Trust Cancer Support
Centre
Helen Davies: 01597 823646

Rhondda Cynon Taf

Royal Glamorgan Stoma Care Support
Group
Domenica Lear 0144 344 3053

Swansea

Swansea Ostomy Self Help Group
Glynis Jenkins: 0179 241 8245

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