

Tidings



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Cover picture

Meet our permanent employees who keep the cogs turning to ensure that the charity is always working towards achieving its mission and vision.

L-R: Jo McKenzie, Clare Matthews, Giovanni Cinque, Jo Hammond, Richard Biddle and Libby Herbert. One important team member is missing from the photo though, our Arvind Anand.

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dear READERS

While looking for new topics to include in *Tidings* we sometimes forget that some of you are facing stoma surgery or in the early post-op days and this is the first issue you will have read. So, I hope that regular readers will bear with us if this time our articles in the Living with a stoma section go back to basics. We have a page of frequently asked questions and two pages of hints and tips for new ostomates. We also look back at when we first had our stomas and what we wish we had known at the time.

My stoma was formed in 1990, eight years before *Tidings* was first published. Around that time, there was a similar magazine called *Your Choice* produced by a manufacturer of stoma products. Reading the stories of how other people coped with their stoma helped me enormously and made me realise that I wasn't alone. I hope that *Tidings* is a similar source of support for you too.

As you may know I am stepping down as editor after this issue. I would like to thank the editorial team for their hard work in assisting me with sourcing articles and in deciding which will appear in the magazine. My thanks also go to health professionals for giving their time to write articles on medical conditions which can lead to a stoma, and for providing advice on stoma management. Most importantly I would like to thank you, our readers, for your letters, stories and other contributions. It is your inspiring and reassuring messages which have made *Tidings* what it is today.

I am delighted that Sarah Squire, our current assistant editor and trustee, and Libby Herbert, our general manager have agreed to become co-editors of *Tidings*. I would like to wish them both every success as they take *Tidings* forward into 2018 under the banner of **Colostomy UK**.

With Best Wishes

Rosemary Brierley
editor@ColostomyUK.org



Hello from your two new co-editors! We are thrilled to be picking up the reins from Rosemary. And, if we are honest, just a little daunted too. Successfully editing a popular quarterly magazine is no mean feat, even when the workload and responsibility is shared between two people. Luckily, we have a great team to help, but that doesn't stop us marvelling at how Rosemary managed to do what she did all by herself. We speak for everyone at **Colostomy UK** when we say a **BIG Thank You** to Rosemary for all her hard work as editor. Maybe now she'll finally have the time to complete the book she started to write some years ago...

Unsurprisingly, Rosemary leaves us in a great place. *Tidings* now has a circulation of around 23,000 and a readership close to 60,000. The issue that you are currently holding is a fitting testimony to her time as head of the editorial team. As you have come to expect, it is packed with interesting stories and letters from ostomates. There are all the usual hints and tips for living with a stoma too, along with news from **Colostomy UK** and articles from healthcare professionals.

Although we come with some fresh ideas for *Tidings*, you'll be relieved to know that we have no plans to change this winning formula. We are very much looking forward to hearing from you, our readers. So, if you have anything to raise, a tip to share or a story to tell, then we'd love to hear from you.

Best wishes,

General Manager

Trustee, Colostomate
and Volunteer

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Colostomy UK

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Reading RG1 4QA

By telephone:

T: 0118 939 1537

Stoma care queries only:

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By E-mail:

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2

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Colostomy UK



We are Colostomy UK

Here if you have questions, need support or just want to talk to someone who lives with a stoma. Your voice on the bigger issues: advocates for your rights and campaigning to raise awareness of what matters to you; running projects to empower you and building communities to support you.

You may have noticed something different about us recently... We are excited to announce that on 16 September, we changed our name to Colostomy UK.

Why change our name?

The reason is simple. Over the past few years we have grown to be much more than just a patient association and so we need a name that better reflects what we do and our ever-growing reach. **Colostomy UK** provides this. It makes a strong statement about our national identity as a charity, while at the same time alluding to the broad scope of our activities. But there is no need to worry, because all of our core services remain the same. We are as committed as ever to helping and supporting people like you. We will always be there when you need us, ready to answer your questions, listen to your concerns, and for those moments when you just want to talk to someone that understands what it is like to live with a stoma.

To accompany our change of name we have refreshed our iris logo, going for a bolder and more contemporary design, and launched a new website www.ColostomyUK.org. We hope you like the new look and find the website easy to access news and information. It's also intended to make contacting us simpler too.

The team at **Colostomy UK** are buoyed by the future. We are looking forward to developing and enhancing the ways in which we help and support you. Additionally, as you may have noticed that over the past year or so, we have started to become much more active advocating for the rights of ostomates and campaigning hard to raise awareness about the bigger issues that affect your day-to-day life. We are now a voice that government, healthcare professionals, businesses and other organisations are starting to listen to. We wouldn't be serving the ostomate community if we didn't make the most of this. We are also running projects aimed at empowering you in a whole host of different ways.

Campaigning and advocacy

Through our Stoma Friendly Society campaign, annual **Colostomy Day** and our increasing exposure in social and mainstream media we have begun to challenge popular perceptions of what it means to have a stoma. Stoma surgery saves and improves lives and we want everyone to know this. Our work is now beginning to have tangible results.

Stoma-friendly society

Up and down the country, shopping centres, sporting venues and visitor attractions have started to improve their toilet facilities for ostomates. Some are also using our toilet signage stickers, which make it clear that not all conditions and disabilities are visible. As members of the UK Toilet Consortium we are also working alongside other charities to lobby central and local government to



improve public toilet facilities. We are campaigning in other areas too. Later this year in collaboration with the Civil Aviation Authority we will be delivering training to passenger-facing staff at airports in the UK. The idea is to help them better appreciate the needs that people with stomas have when travelling and, where necessary, enable security officers to engage and communicate with ostomates in a sensitive and understanding manner.

Colostomy Day



Our annual awareness day – **Colostomy Day** – is growing year on year; fighting the poo taboo and educating the public. This year our focus is on super stomas and raising awareness of how stoma surgery is life saving and life changing.

Projects and communities

Our projects are all about empowering individuals and the ostomate community more widely to live full and enriching lives.

Active ostomates

Following last year's successful pilot we have commenced a broader roll-out of our 'Active ostomates' programme. Support groups around the country are now organising walking activities and running chair yoga sessions. Group exercise has proved particularly popular with people who aren't confident enough to try an activity on their own or are unsure about

the level of physical activity that is safe following stoma surgery. People who prefer to 'work-out' in the comfort of their own home are covered by the range of exercises detailed in our booklet 'Active Ostomates'. We have further initiatives planned for 2017/18, including **Team Colostomy UK** and our own exercise DVD – so there really won't be any excuses not to get active again.



Caring for Colostomates

Our Caring for Colostomates project has been helping to provide carers with practical advice and support on caring for someone with a stoma. Due to the success, we plan to expand this in the next few years.

Stoma aid

Since its launch in 2015 this project has gone from strength-to-strength. By the end of October 2016 we had distributed

a staggering 182,080 surplus stoma bags to ostomates in developing countries. As you will know if you have managed to read the regular updates in *Tidings*, the importance of this project and the difference it makes to people's lives cannot be understated.

Communities and support groups

Our closed Facebook support group continues to grow and provides invaluable support and friendship to the 4500+ members. We plan to develop more communities like this to support you. Our plans include, regional meet ups, special events and helping local support groups.

We'll be launching lots of new initiatives in the coming year so keep an eye out for them. In the meantime if you have any questions please email clare.matthews@ColostomyUK.org

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Bulletin Board

Open Day 2017

A big thanks to everyone who attended our Open Day. And what a day it was too. There was a real buzz, but that's what happens when you gather ostomates, manufacturers, stoma care nurses and speakers together in the same place! For those of you that couldn't make it, we'll be publishing some photos of the day in the next edition of *Tidings*. These will include some snaps of our ever popular fashion show, so you can see for yourself just how sensational the models looked. All in all, the day was a fitting way to celebrate our 50th anniversary. It was also just the occasion to announce the big news of our rebranding as **Colostomy UK**, which you can read more about in more detail on page 6 and 7. Once again, thank you to everyone for making the day so special.

Colostomy Day – Saturday 7 October

We're confident that this year is going to be a great success. At the time of going to print we already know that lots of you are preparing to celebrate your super stoma and tell the world how it has improved and in some cases even saved your life. The day is all about raising awareness by sharing positive stories. We are hopeful that our hashtag **#superstoma** will create something of a stir on social media. If you're reading this before 7 October then there is still time to get involved... remember, every time someone likes or shares a superstoma story on Twitter and Facebook, more people are reached. Please tell us what you did and send us the photos!

Association of Stoma Care Nurses (ASCN)

We attended the ASCN Annual Conference (30 Sept – 3 October). It was a great opportunity to let stoma care nurses and other health care professionals know about our new name and all the ways we can support them and their patients.

Wendy Hetherington

It is with great sadness that we announce the passing of **Colostomy Association** trustee Wendy Hetherington, who passed away in August after a short illness.



Wendy was a wonderful, caring and enthusiastic trustee and was the driving force behind our Junior Ostomy Support Helpline (JOSH). Her passion for helping parents of children with bowel disorders leaves a legacy that ensures that no parent feels alone and has someone they can reach out to for support. She will be sorely missed by all the trustees, office team and volunteers at the **Colostomy Association** and our condolences are with Wendy's family and friends at this time.

Our name change to Colostomy UK

Please note the following:

If you donate by standing order this will still go through as normal as our bank details have not changed.

Our postal address stays the same

We can still accept cheques made payment to **CA Ltd** or **Colostomy Association** but you can also make them payable to **Colostomy UK**.



Hello to all my fellow ostomates



"One of the happiest days of my life, sharing my son Ashley's 21st birthday. A day I thought I would never see."

I live in a lovely, little village called Llŷs-Y-Fran in West Wales and run a holiday cottage business. My husband is Gareth and we have two children, Ashley and Ryan. Both are currently at university. It will be seven years this year that I have had my colostomy – named Rose Bud by the way.

I was 47 when my life was turned upside down. Did I think I would be here today? No! Did I think I would cope with the colostomy? No! These were the thoughts going through my mind that I couldn't share with anyone at that time.

It all started way back in 1998 when I was diagnosed with irritable bowel syndrome. I had suffered on and off with bouts of diarrhoea and sometimes a little blood loss but put this down to piles. I was always looking for the nearest toilets. In 2010, during a visit to Washington DC for a family wedding, I wasn't very well. At first, I didn't say anything as I didn't want to spoil the trip but a few days later I was worse and couldn't go five minutes without needing the loo. I will never forget my youngest boy, Ryan, cuddling into me and asking me to promise him that I would go straight to the doctor when I returned home.

The day I arrived home I had an appointment with Dr Evans who examined me straight away. We looked at each other and I knew what was coming. She arranged for a colonoscopy at the local hospital,

Withybush in Haverfordwest, the next day. Gareth dropped me off and within the hour they were calling him back and I was taken into a room and told that it was Stage 4 cancer. My whole world fell apart with just one sentence!

Just two days after seeing Dr Evans I had an appointment with a consultant, Mr. Umughele, who explained everything but of course I didn't take in any of the information. I spoke to my best friend, Tracy, who is a cancer nurse specialist and she came with me to see Mr Umughele at the hospital. I would always recommend taking someone with you as you have so many questions and so much information to deal with that it is impossible to understand or deal with it on your own. Tracy was there at all times to support me and put me right on the information I hadn't grasped.

The consultant said that it was a large tumour and once he had removed it I would have a stoma and he wouldn't be able to do a reversal. We had to go away and take all this devastating news on board whilst he started arranging all the necessary treatment.



Ryan with his mother's Chemo Calendar.

I had to tell our two boys: 12 year old Ryan, who had just started high school and 14 year old Ashley, who was just starting his GCSEs. It was quite possibly the most difficult and hardest and saddest thing a mother has had to do. My world was turned upside down in just a few days.

Mr Umughele said they needed to start treatment straight away and this would be possible at the Singleton Hospital in Swansea. Tracy and I looked at each other and we knew what decision to take without even speaking. That's best friends for you! Everything was moving so fast. Gareth and I were in the car travelling to Swansea a three-hour round trip the next day.

At Singleton Hospital, they decided that the treatment would be 25 chemo and radiotherapy sessions to start straight away. Wow! We really didn't know how we all coped with this. Gareth didn't know what to do with himself. Ashley took to his bedroom and was very withdrawn and Ryan clung to me like glue. Ryan sorted out the vast amount of tablets and made sure I took them on time. He even made a calendar like a Christmas Advent calendar with 25 days on it so that we could cross off the days I had treatment. The car journey to and from the hospital seemed longer each day towards the end of the chemo treatment.

I knew I was starting to get weaker as the treatment progressed but always tried to remain positive and not show my true (scared) feelings. But on day 22, I could feel my life draining away, I phoned the hospital and can remember the doctor asking me if I was on my own. I replied my family were downstairs so she asked for my address and told me to sit with my family. It's now a bit of a daze to me. This is what my family told me happened next ...

Normally it takes about twenty minutes to get to my house out in the countryside, but Gareth said the doctor was there quite quickly. She said it would take an ambulance too long to reach me so they decided to put me in the car and get me to

Withybush Hospital. It was there that they told Gareth that I had sepsis and toxic poisoning! I was extremely poorly and as it was worsening by the hour they didn't know if I was going to make it through the night.

It was about four days after that I started to realise I was still here and was coming out of this nightmare. Because I was very ill, Mr Umughele had made the decision to keep me in hospital and stop the chemo and radiotherapy treatment.

On June 8 2010, in Withybush Hospital, Mr Umughele performed keyhole surgery to remove the cancer, seal up the bowel and create the stoma. This took 13 hours. I was in recovery for a few days and then went back to ward 10. The staff became like a family to me and I can never thank them enough for looking after me. Jane, my stoma care nurse, came to see me and talked me through everything. What a lovely, dedicated nurse, but one very busy lady as she was the only stoma care nurse at Withybush Hospital at the time.



Rosemarie on holiday in Tenerife

Mr Umughele told me that the operation was a success and as I say: "the cancer was in the bin". I was, however, left with a problem that we didn't anticipate; I didn't know when I needed a wee! The only way I could go home was with a catheter but both Mr Umughele and I agreed I had been in hospital far too long and I needed to be with my family.

Here I was at home, happy and relieved. But No! I was still scared about how I was going to cope with this Bag for Life. There were loads of things going on in my mind. Would I be able to do all the things I did before? Would I be able to wear the same

clothes? Would I be able to go on holiday with my boys? Then one day I just thought: "What does it matter? I'm here!"

I'm a very active person and don't like to sit still, I like to be doing something and am a bit of a tomboy and do all the DIY jobs around the place. Now I don't recommend this to anyone but I almost went straight back to work! Six weeks later I was up on a roof fixing a leak!

I do regret doing heavier work than I should have as I now know that was probably the cause of my hernia. I feel we should be told about how many people who have stoma surgery end up with hernias as this wasn't really talked about until it was too late for me.

The first few months were the hardest although Jane, my stoma care nurse, said I could phone her any time with any issues. However, I did feel that as I had noticed, first-hand, how busy she was I didn't want to bother her. I just got on with it and only decided to contact her five months later to ask about irrigation. She said I could do it and if I wanted to give it a go she would be in touch. Eleven months after my operation she came to show me how it was done.

Well! What a difference! This has completely changed my way of living. I am now in charge of my stoma, instead of my stoma being in charge of me, I can wear support pants without my bag pancaking and have less wind! I can do many other things knowing my bag isn't full or about to fill, and I can travel without wondering where I can stop to change my bag.

I am happy with my Rose Bud and never embarrassed to talk about my experiences or wear a bikini on holiday although I have made a white cover for my bag that makes me feel like she is covered up.

I've told you I live in the country and feel that at the beginning of this long road I really could have done with some extra support. My family and friends were there for me of course and I was lucky to have my friend Tracy, who is my rock; she gave me support and also medical advice. I came across the **Colostomy Association** when I searched the web back in 2010. It was *Tidings* magazine that gave me hope and helped me through some difficult times at the beginning of my journey. Just reading the stories and knowing that there is life after 'the bag' was just what I needed.

There is now a support group in Pembrokeshire which was founded by a gentleman called Roy and when I found out about this I went to a meeting. I am now helping as much as I can as I know full well we need these groups to share stories and help others.

Rosemarie Rees-Paton

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What we wish we had known when we first had our stomas



Sarah

Colostomy 2007 due to a rectovaginal fistula

I wish I had known:

- ❖ that I would be able to irrigate and regain control;
- ❖ that I would still be able to eat the same foods as before;
- ❖ that I would still be able to go on family holidays and go swimming; and
- ❖ that nobody would know I had a stoma unless I told them.

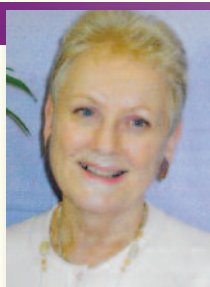


James

Colostomy 2014 following emergency surgery for diverticulitis

I wish I had known:

- ❖ that my stoma would inspire me to appreciate life more and make me more determined in certain situations and would not hold me back;
- ❖ not to panic about returning to work specifically staying away on business. My first thought of "how will I cope" was irrational (but understandable);
- ❖ that I would cope so well. Three years on and I've not had a reversal, I didn't think that would be the case at the time; and
- ❖ about the wide range of support available, from local colorectal nurses to the **Colostomy UK**.



Jackie

Colostomy 2001 due to bowel cancer

I wish I had known:

- ❖ that I was not the only one; there are more than 100,000 people with a stoma in the UK;
- ❖ that in the early days, other people also lack confidence and feel reluctant to go out – it wasn't my fault;
- ❖ that the **Colostomy UK** could have arranged for me to see or speak to someone else with a stoma; and
- ❖ how much difference attending a local support group meeting could make.



Ian

Colostomy 2011 due to bowel cancer

I wish I had known:

- ❖ how important it was to wear a support garment and to be careful when lifting;
- ❖ that irrigation would give the confidence to forget about my stoma all day;
- ❖ that there was so much support out there from the **Colostomy UK** and on their facebook group; and
- ❖ that after all the surgery and chemo I would be able to regain my fitness and cycle further than I ever had before.



Rosemary

Colostomy 1990 due to a rectal prolapse

I wish I had known:

- ❖ that one day I would wake up in the morning and my stoma wouldn't be the first thing I thought about. Later I would go through a whole day without giving it a thought;
- ❖ that having a stoma wouldn't stop me getting married again;
- ❖ that having to change a bag wouldn't stop me travelling. I would camp under canvas and cope with long haul flights. I would do a bag-change in a portable toilet cubicle at the top of Table Mountain in Cape Town; and
- ❖ that the sore skin would clear up and the skin around my stoma would, once again, be unblemished.

Hints and Tips for New

Changing your colostomy bag

When cleaning around your stoma, it is not unusual for slight bleeding to occur. If, however, there is blood coming out from inside the stoma it is important to seek medical advice.

Before applying your bag/flange, put it in a warm place e.g. on top of a radiator or under your arm for a few minutes to improve adhesion.

Standing upright while applying your clean bag will help to eliminate folds and creases and ensure a good seal on flattened skin.

When fitting a one-piece bag bend the top half of the flange away from the body so you can see to fit the bottom half accurately around the stoma, then press the rest of the flange into position. You may find it easier to position your flange correctly if you stand in front of a mirror.

Stomas can change in shape and size, especially during the first few months, so check weekly for any changes. Place the backing paper that you remove from the flange over your stoma then look in a mirror to check that the hole is the right size.

There should be a 1–2mm gap around your stoma. If the hole is too big this can lead to sore skin. If it is too small the flange will rub up against the side of the stoma, or the adhesive may not stick securely, allowing motion to collect behind the flange and cause leaks.

Hairs around the stoma site can impair flange adhesion. A small electric razor gives a really smooth shave and is much safer than an ordinary razor. To protect your stoma while shaving cover it with the cardboard tube from inside a toilet roll or the lid of a small aerosol (i.e. adhesive remover spray).

Before using a new type of appliance, patch-test it on a small area – the other side of your tummy is best – in case of a reaction to the adhesive.

A bag can be left in place while you have a bath or take a shower. Some people with a colostomy prefer to take their bag off while in the bath or shower, but remember to choose a time when your stoma is less active i.e. before rather than after a meal.

Changing your bag away from home

Don't forget your emergency kit when you go out. It can be just a spare bag and an adhesive removal wipe inside a disposal

bag in a pocket or the zip-compartment of a handbag or you may prefer to carry more supplies in a make-up bag or similar discrete container.

People who have a stoma are entitled to use accessible toilets where there is a wash basin and a bin for disposal on hand. See page 35 for details of how to obtain a RADAR key which opens locked toilets all around the UK.

When you know you may have to change your bag in a toilet cubicle where no running water is available, wet wipes or a small spray bottle filled with water may be useful. Some stoma appliance companies

Emergency Kit



- Stoma bags, the flange already cut to size. If you are going to be away from home for a considerable time and/or are concerned that your output may be looser than normal it may be useful to include a drainable version of your usual bag, just in case.
- Adhesive remover (wipes take up less space than an aerosol).
- Dry wipes.
- Wet wipes, a small (spray) bottle of water or a sachet of cleansing gel in case water is not available.
- Other additional products that have been recommended by your stoma care nurse.
- Disposal bags.
- Mini air-freshener/odour-eliminator spray.

Remember to check the contents of your emergency kit and renew bags and other products on a regular basis.

Ostomates

produce sachets of gel for cleaning around the stoma.

Clothes peg(s) can be used to keep your clothes out of the way while you remove your bag and clean around your stoma.

Used bags can be disposed of in sanitary bins in Ladies toilets.

If you are concerned about disposing of bags while away from home, a stoma bag with a liner, which contains the waste and can be flushed down the toilet, is available. Check with your stoma nurse if these flushable bags, produced by Clinimed, would be suitable for you.

If you use a drainable bag, try flushing the toilet before you use it, just to make sure that the flush is actually working.

Dealing with:

Odour

Most stoma appliances have a filter which incorporates a deodorizer, so odour shouldn't be a problem. However, if you are not happy with the filter on the bag you are currently using, there are other bags made by different manufacturers that you could try.

Odour could mean leakage or the filter may have come into contact with the contents of the bag making the deodorizer ineffective. If you suspect this is the case change your appliance as soon as possible.

If you are concerned about odour while changing the bag:

- Spray an air-freshener/deodorizer in the bathroom/toilet cubicle before you remove the bag and again before you leave.
- Put drops or granules designed to neutralize any odour (available from manufacturers and suppliers of stoma care appliances) or a Tic Tac mint into a clean bag before you stick it in place.

Ballooning

This occurs when wind becomes trapped inside the bag causing it to inflate.

Wind that escapes through the stoma should be slowly released through a filter usually placed near the top of the bag.

Filters vary in efficiency so if you find that your bag regularly inflates it is worth trying other bags to see if the filter is more effective.

A filter can become blocked if it gets wet:

- To keep the outside dry, place a sticky patch (supplied inside a box of bags) over the filter when you take a bath or shower and when you go swimming.
- If the inside of the filter becomes wet because it comes into contact with the stoma output it's time to change your bag.

Using a two-piece, clip-on closed bag or a drainable bag will allow you to release wind without changing the bag.

A one-piece closed bag with an integrated vent that can be unclipped to release wind is now available from Clinisupplies.

Pancaking

This occurs when the output collects around the stoma instead of taking a downward turn and falling to the bottom of your bag. One of the reasons this happens is because there isn't enough air in the bag.

To help the motion to fall to the bottom of the bag:

- Cover the filter with one of the sticky patches that are supplied in each box of stoma bags. This will keep air inside the bag, but if the bag begins to overinflate you will need to remove the cover from the filter to allow the gas to escape.
- Lubricate the inside of the bag with baby oil or one of the many products available from the various supply companies.

Squirt a little oil or gel into your bag and give it a good rub around before you stick it on. Take care not to get any oil or gel on the adhesive as this can reduce the effectiveness of the seal.

- Before you put it on check that the back and front of the bag are not stuck together by pushing a finger through the hole in the flange to separate them.
- Place a scrunched-up tissue inside the bag to keep the two sides apart.
- Stoma bridges (small foam cubes which can be stuck on the inside of the pouch to keep the two sides apart) are available from Opus healthcare.

Sometimes pancaking can lead to faeces leaking between the flange and the skin. Always check that the flange is firmly sealed around the stoma, but if leakage continues consult your stoma care nurse.

Leakage

Ask your stoma nurse about:

- Products which can help to give a really good seal around the stoma.
- Alternative bags.

Remember:

Some medications may change the output from your stoma:

- Antibiotics may cause diarrhoea.
- Painkillers may cause constipation.

Enteric coated or modified release tablets are designed not to dissolve until they have reached the latter part of the intestine, so they may appear unaltered in the stoma bag without having any therapeutic effect.

Your doctor or pharmacist will be able to advise you if alternative medication without these side effects is available.

To minimize the risk of developing a parastomal hernia, speak to your stoma care nurse about support wear.

Frequently asked Questions

What can I eat now that I have a colostomy?

Just because you have a colostomy it does not mean you have to change what you eat. In the first four to six weeks after surgery, to give your bowel a chance to recover from the operation, you will probably be advised to eat little and often and to avoid foods which are high in fibre. It would also be worth being careful of foods with skins and pips. When you have fully recovered you should be able to return to enjoying a normal, healthy, balanced diet.

If as time goes on you suspect a food may be causing a problem i.e. wind or a loose output, check that this really is the culprit before you cut it out altogether. The best way to do this is to keep a record of the food you have eaten and the symptoms you experience.

However, a word of warning to new ostomates. Don't always assume that a particular food was responsible for one bad experience. It may just be coincidence so do try it again at least three times separated by at least a week. It's not necessarily what you eat, but how often you eat and how much. Your stoma will work best if you eat regularly; three small meals each day are better than one large meal in the evening.

And remember, we are all different. Colostomies are formed for a variety of reasons such as cancer, diverticulitis, Crohn's disease etc. and in some cases a health professional may recommend a diet for an underlying medical condition.

For more information, the leaflet *Healthy Eating: nutritional guidelines for people who have a colostomy* can be obtained from the **Colostomy UK** 24-hour free helpline: **0800 328 4257** or downloaded from **www.ColostomyUK.org**

How will I manage when travelling abroad?

Make sure you plan ahead. In the weeks leading up to your holiday, order sufficient stoma supplies. It is also important to check that your travel insurance covers pre-existing conditions; if not inform the insurance company about your stoma

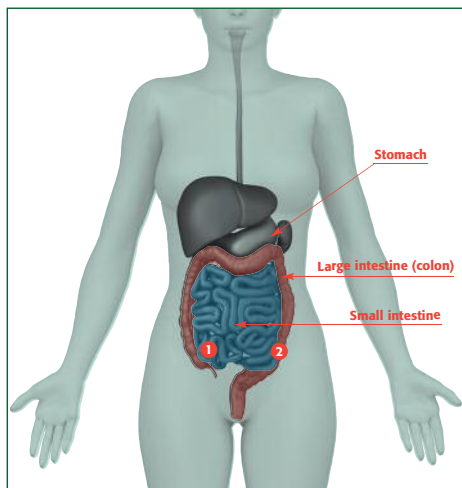
Pack twice as many stoma bags as you think you will need in case of change in bowel habits while away or travel delays. Include your supplies in your hand luggage. If you take a small aerosol e.g. adhesive remover it must be inside a transparent resealable bag which you must remove from your hand luggage at security and place in a tray for X-ray.

At the airport, if there is any output in your stoma bag it is advisable, if possible, to change or empty it before you go through security. Of all the people with stomas who travel abroad every year, only a very small minority get stopped. Although it isn't essential to take a travel certificate or a letter from your doctor that explains you have a stoma, it can be useful to have one in your hand as you go through the scanner, just in case.

While away, dispose of used appliances as you do at home. It is acceptable to place a double-wrapped bag in the bin in the bathroom. You may, however, prefer to empty it first; using a drainable bag makes this easier. Another option is a bag with a liner that can be flushed down the toilet. If you think it would be helpful to use a different type of bag while you are on holiday it is important to trial it for a couple of weeks before you go to make sure it is suitable for you.

For more information, the leaflet *Travel advice* can be obtained from the **Colostomy UK** 24-hour free helpline: **0800 328 4257** or downloaded from **www.ColostomyUK.org**

What is the difference between a colostomy and an ileostomy?



- 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.

Regain control of your **skin health**...

If you answer **'Yes'** to any of these questions, contact us today.

Please tick ✓

☐

Is the area around your peristomal skin red, moist and painful?

☐

Have you tried different seals with little or no success?

☐

Do you feel having poor skin is something all ostomates have to put up with?



+

TRE Seal

☐

Do you have a body shape which makes pouch adhesion problematic?

☐

Does your skin barrier lift or roll around the edges?

☐

Do you suffer from excessive leakage?



+

X-Tra Strips

☐

Does removing your pouching system leave your skin red and sore?

☐

Do you get adhesive residue remaining once you remove your pouch?



+

EasiSpray

To discuss your answers, return this page to **FREEPOST DANSAC** or call FREE on **0800 581117**

Name: _____

Address: _____

Postcode: _____

Tel: _____

Email: _____

You have provided your consent to Dansac Limited and all other companies in the same group of companies, to use your personal contact and medical information (in particular your name, address, information about your medical condition and medical products and services you need or desire) in order to contact you by postal mail, by email or telephone (including SMS (text) messaging) to inform you about the Hollister Group and their products and services. For this purpose, Dansac Limited may also transfer your information to other companies of the Hollister Group in the UK, Europe and the United States. You accept that your personal data may be stored and processed in any of those countries and/or on secure computer servers (including what are known as "Cloud" servers) used by Hollister Group companies in the UK and abroad (including outside of Europe). Your consent is optional and can be withdrawn at any time by contacting: **Dansac Customer Services 0800 581117**.

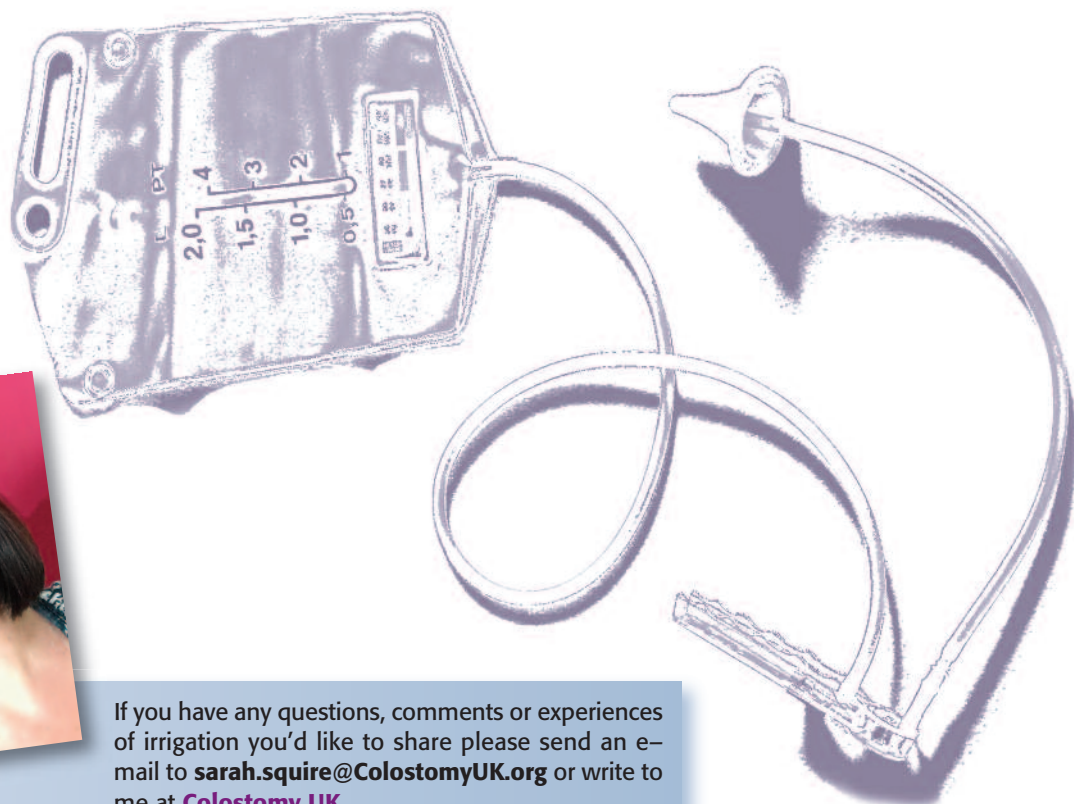
I have read and agreed with the Terms & Conditions ☐

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FREEPHONE: 0800 581117

Discover more at [dansac.com](https://www.dansac.com)

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Dedicated to Stoma Care



If you have any questions, comments or experiences of irrigation you'd like to share please send an e-mail to sarah.squire@ColostomyUK.org or write to me at **Colostomy UK**.

Sarah Squire

Irrigation and You

I often hear a good friend of mine refer to irrigation as the “Gold standard of colostomy management”. Steve Clark is a great advocate for irrigation as it made such a difference to his life. Not all colostomates are suitable for irrigation and others choose not to try, but for those who irrigate successfully it can be life changing. For me I liked being in control of my stoma and the fact I could then almost forget it for most of the day. However, when I considered trying irrigation I thought it sounded like it would be a real faff. Nobody would give me a definite method, and as a scientist, I wanted a step-by-step protocol which would work each time. But I did decide to try it and you know what, those who had advised me were right, you find what works for you. Your technique will probably be slightly different to others but then our diet, bowel and lives are different to others too so it's not really surprising one method doesn't suit all.

As I learnt the process of irrigation and began adapting it to work for me I had lots of questions. Through my involvement in **Colostomy UK** and through social media I now realise lots of people have similar queries. I thought this time I would go over a few of the common issues that come up in the hope that I can answer some questions before they arise for new irrigators and maybe even help a few of the old timers – I know I still learn from others after 10 years.

Let's start with the irrigation kit. Whether you prefer one type or another, they all do a similar job. You may use a pump or a gravity system, it may come with a thermometer, a whizzy wheel in the controller or not. But what they do all have in common are tubes, and tubes get mouldy as there is always that little drip of water in there which sits between irrigation sessions. I hang my kit to dry but I still see little bits of mould appear after a few weeks. A simple way to prevent this is

to soak the kit in a sterilising solution such as Milton (own brand alternatives are cheaper!). This can be done every week or so, or when you see the first sign of mould. The kits are designed to be used for three months although I must say they are pretty hard wearing and with regular cleaning I've seen them go on for much longer.

Water is always a topic of discussion. How much, how hot and how to stop it spilling

on the floor – although the last one may just be me! Again I wanted to be told how much water to infuse and was told you learn to feel how much. Really? I wasn't sure that could be the case. Your stoma nurse will guide you as to how much water to use but then you really do learn to feel how much is enough. For me, I feel 'full' after about 700mls but this can change – I assume depending on how full my colon is, but it does vary day to day. I tend to use two to three infusions of water, letting the water and waste out in-between. I know for some once is enough, but for me a lot of the poo comes out in the subsequent infusions. Again this would be something to discuss with and be guided by your stoma nurse.

Literature states that the water used for irrigation should be body temperature although anecdotally we know a lot of people use it a little warmer. If the water is too cool you may get cramps and find it hard to get the water in but too hot and it could do damage to the bowel. I was taught to hold my hand in the water and if it felt comfortable it was OK. As for keeping the water in the kit and not on the floor I just need to learn to look what I'm doing rather than trying to watch TV on the iPad! Clearly, I am not as good at multi-tasking as I thought! Oh and do ensure the irrigation sleeve is in the loo before you start – again user error on my part but

Irrigation is a method of colostomy management which involves using specialist equipment to introduce warm water into the bowel via the stoma. The water causes muscular contractions (peristalsis) within the bowel which in turn cause expulsion of its contents.

Many Ostomates prefer this method of colostomy management as it gives them a sense of control. If you feel you would like to try irrigation you should first contact your stoma nurse to see if you are a suitable candidate. If you get the go ahead they will then arrange a time to teach you. For more information see the **Colostomy UK** website or purchase the *Irrigation and you* DVD using the form below.

I have been known to be engrossed in my book or TV show and not realise the sleeve is on the floor instead of dangling in the loo.

The discussion on water brings us onto travel. The general rule is that if you are able to drink the tap water you should also be OK to use it for irrigation. Normally in countries where bottled water is the norm it is very cheap to buy. I take a travel kettle with me to warm some which I then add to room temperature water to get it just right. I also have an S-hook which has served me well on my travels. A handy shower rail or door makes hanging the water reservoir easy. I do also carry a sticky 'Command' hook which will stick to most things, just in case I have nowhere for the

hook although that's only happened once in 10 years.

I think I could write a book about the ins and outs of irrigation but alas I only get two pages. So I can't cover everything but hope these few points will have helped some people plus I would love to hear from readers with their hints and tips. And I'm going to leave you with a question: Fellow trustee and irrigator Ian Jackson has found that during the hay fever season his irrigation doesn't last as long. Could this be the antihistamines he takes or something to do with the hay fever itself? Does anyone else notice this effect? I'd love to hear your experiences.

Happy irrigating!

Colostomy Irrigation and You DVD

Order Form Colostomy Irrigation and You (Patients)

Colostomy Irrigation and You is an educational DVD aimed at patients, it has been produced by the **Colostomy UK** 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 price of £4.99 (incl postage and packing) simply fill in your details below and return it with your cheque made payable to the **Colostomy UK**, to:

Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire RG1 4QA



Title:

Name:

Address:

Postcode:

Tel:

Email:

Please allow 30 days for delivery.

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

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

Fund raising Focus

2017 Raffle

Issue 45 contained two books of tickets for the 2017 **Colostomy UK** annual raffle, and this year there's an even greater chance to win! We've still got our fantastic first prize of £2,500, second prize of £500, and four chances of winning £250, but there are now five chances to win £100 as well. What better way to start the new year than spending your winnings in the sales or on a last-minute holiday!

Tickets are £1 and all money raised from the raffle will go towards supporting vital **Colostomy UK** services such as our 24-hour free helpline, free literature and *Tidings* magazine.

We've had a brilliant response so far, and if you haven't returned your tickets yet there's still plenty of time to do so.

All completed stubs need to be in by **Friday 15 December** and the winners will be notified by email, phone or post and announced in the spring 2018 edition of *Tidings*.

Please note there is a printing error on the stub of the tickets. The date of the draw is stated as taking place in 2016 rather than 2017. The draw date is correct on the ticket portion that the purchaser keeps. The fundraising regulator and the Gambling commission have both confirmed that these tickets are valid for sale.



Brian's Queensferry crossing challenge

Ostomate Brian Chalmers is raising funds for **Colostomy UK** by walking over the new Queensferry Crossing on 3 September. You can Support Brian and read more about his challenge here www.justgiving.com/fundraising/brian-chalmers1

Singing for Colostomy UK



Musician Jim Mitchell is donating all proceeds from the sale of his 'Do You Remember Me' CD to **Colostomy UK**. For more details and

to buy a copy visit his website at <http://www.jimmitchellsongs.co.uk/albums/do-you-remember-me>

Thank you

Yet again our supporters, their friends, and family members have been busy raising funds for **Colostomy UK**. As always we are hugely grateful and humbled by the efforts of so many people who help financially support our various services.

Peter Dulce raised **£265** as part of his 90th birthday celebrations

The Parkside Colliery Male Voice Choir raised **£40** from a raffle at their annual bowling competition

Caroline Emeny raised an amazing **£717** from her music quiz that we told you about in *Tidings* Issue 45

Simon Kocziban ran the Bristol 10K on behalf of Stoma Aid in May, and managed to collect a fantastic **£900!**

Unity Lottery



Colostomy UK are very pleased to announce that as of 1st July 2017, the **Unity Lottery**, through which we run the **Colostomy UK** lottery, will be implementing a new prize for a 3 digit number match of 5 Prize Entries!

This means that going forward, the £5 cheque will be replaced with 5 Prize Entries into the next draw. So, every time you get a 3 digit number match to your lottery number, you will automatically be entered for 5 Prize Entries into the following weekend's draw.

Why it's great for you

You get 5 more chances to win up to £25,000 in the next week's draw, and know that your charity is reaping the rewards too. 5 Prize Entries also means no more £5 cheques to take to the bank.

Why it's great for us

Your charity will receive at least 50% profit on the additional 5 entries won instead of a £5 prize – so every time you win against a 3 digit number match, your charity will earn an additional £2.50. This will make a huge difference to their profit week by week!

Your Questions

What happens now?

The change from the £5 cheque to 5 Prize Entries will be implemented as of 1 July 2017. There's nothing you need to do from your end, as this will be switched over automatically. From this date, every time you get a 3 digit number match, you will be entered for 5 Prize Entries into the next draw.

How will I know I've won?

As usual, you will receive a letter notifying you of your win. Instead of a £5 cheque at the bottom of the letter, you will be issued with 5 new lottery numbers which will be

entered into the draw the following week, for that week only. If you're lucky enough to win against another 3 digit match, you will be sent a further 5 lottery numbers the following week and so on. And if you're even luckier to win against a 4, 5, or 6 digit number match, you'll be sent your winning cheque in the post!

Do I need to claim my prize?

All prizes will be issued automatically, so there is no need to claim.

Where can I find more information about the change?

You can find the updated Unity Rules at <http://www.unitylottery.co.uk>. You can also get in touch with the Unity team if you have any questions on **0370 050 9240**, or email info@unitylottery.co.uk.

We hope that you will be as excited about this change as we are! Thank you for being a part of the **Colostomy UK** Unity lottery. Your contribution to our lottery means that we can continue to raise essential funds for our cause.

Good luck!

Grants and Trusts

Colostomy UK is grateful to the following trusts, foundations and businesses who have recently agreed to support our work through contributions to our core costs and various projects:

The Shanly Foundation, The N Smith charitable settlement, SC Johnson, The Prudential PLC, The Joseph Strong Frazer trust, The Roger Vere Foundation, The W O Street charitable foundation, The Hospital Saturday Fund.

Textgiving

You can now make a donation to **Colostomy UK** 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 **Colostomy UK**.

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

Leave a Legacy



WHAT WILL YOUR LEGACY BE?

Giving in your will is a truly special way to make a lasting difference. It will help ostomates of tomorrow, their family members and carers, receive life-changing support from **Colostomy UK**.

What your gift means

Legacies large and small can have an extraordinary impact for all the people we help and support. They can:

- Ensure there is always a voice at the other end of the phone
- Train volunteers to provide support at open days and in hospitals
- Fund our campaign for a stoma friendly society.
- Make sure the ostomates of tomorrow receive the same support from us that you have

How to leave a legacy

A solicitor can help you to write a will or, if you already have a will, a codicil. Your legacy could be used wherever it is most needed or you can choose to support a specific area.

Your solicitor will need the following information on our charity:

Name: **Colostomy UK**

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

Charity Commission registration number: 1113471

After you have provided for your loved ones we hope you will consider a gift to our Charity.

Win up to £25,000 with Unity

50p
from every £1 goes to
Colostomy UK

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

How it works

For just £1 per week you will be allocated a six digit **Unity** lottery number. You can purchase more than one entry if you wish. Every Saturday, the lucky winners are selected at random and the prize cheques posted directly to you, so there is no need for you to claim. You must be 16 or over to enter. Winners have to match 3, 4, 5 or all 6 digits of the winning number in the correct place in the sequence.

How to join – three easy steps

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

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

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

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

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

Or by phoning the Unity winners hotline
0370 055 2291

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

Prizes	£25,000 6 digits	£1,000 5 digits	£25 4 digits	5 Prize Entries 3 digits in the next draw
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1. Your details (please print in block capitals)

Title:	First Name:
Surname:	
Address:	
Postcode:	
Tel:	Mobile:
D.O.B.:	If you would like to receive correspondence via email, please tick here <input type="checkbox"/>
Email:	
<input type="checkbox"/> If you do not wish your name to be publicised if you win, please tick here	

2. Payment Frequency


How many entries would you like each week?

How often do you want to pay?	<input type="checkbox"/> Monthly	£4.34 Direct Debit only
	<input type="checkbox"/> Every 13 wks	£13
	<input type="checkbox"/> Every 26 wks	£26
	<input type="checkbox"/> Every 52 wks	£52

(please tick payment frequency and write amount in box)

Total Payable

3. Select your Payment method

<input type="checkbox"/> Payment by Cheque	<input type="checkbox"/> I enclose a Cheque made payable to Unity (minimum payment £13)
<input type="checkbox"/> Direct Debit Please fill in the form and return to Unity Name and full postal address of your Bank or Building Society.	
To: The Manager: Bank/Building Society	
Address:	
Postcode:	
Name(s) of Account Holder(s)	
Branch Sort Code:	
Bank/Building Society account number	
Banks and Building Societies may not accept Direct Debit instructions for some types of accounts.	
unity Instruction to your Bank or Building Society to pay by Direct Debit 	
Service User Number Reference: 4 2 1 1 0 2	
Instruction to your Bank or Building Society Please pay Unity from the account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this instruction may remain with Unity and, if so, details will be passed electronically to my Bank/Building Society.	
Signature: Date:	

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

Signature:	Date:
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Detach the form, put it into a stamped envelope and return to **Unity** at the address shown on the right. They will notify you of your **Unity** lottery number.

Post this form in a stamped envelope to:

The Unity Lottery
Furness Gate
Peter Green Way
Furness Business Park
BARROW-IN-FURNESS
LA14 2PE

For office use only:

T46



Get your Colostomy UK 2018 Calendar

The calendar competition results are in... so prepare for your virtual holiday!

Ever sat there on a cold miserable day and wished you were somewhere else? If so, then our 2018 Calendar is just the ticket. Spiral bound and measuring 210mm x 420mm, each month opens to reveal a stunning photograph which, with a little imagination, will see you jetting off to faraway places. We have everything covered, from cityscapes to sunsets in tobacco coloured skies. There is also plenty of space to record appointments and even, perhaps, the date of your 'real' holiday.

Our calendar competition received a total of 96 entries and, just like last year, the standard was so high that it caused our judging panel a few headaches. Every single photograph was taken by one of our supporters. Mr Kevin Young was the eventual winner with his photograph of a sunset near Stromness, Orkney, Scotland. Second and third place went to Mr Trevor Andrews and Mrs Phyllis Oliver respectively, with photographs of Castillo de Casares, Málaga, Spain and Yardenit Baptismal Site along River Jordon, Galilee, Israel. They say that a picture is worth a thousand words. We couldn't agree more. Those that make up

our new calendar are more than just visually stunning. They are also tangible evidence of ostomates living full and active lives.

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TIDINGS | AUTUMN 2017 | 23

Seventy-eight and



Gilbert with his wife, Doreen, and their four children

I was 72 years of age when I received my second postal screening test for bowel cancer. My first, two years earlier, was negative. As I was showing no bowel cancer symptoms and leading an active life I was quite sure the second time around would be negative also.

A week after sending off the test I received a reply that it showed an abnormality. A further test confirmed that all was not well and within days I was seen by a nurse at Hull Royal Hospital. She very thoroughly explained about bowel cancer, the suspected cause of the abnormality in the tests.

Events now started to move very quickly and within a week I had an appointment at Hull Hospital for a colonoscopy. I still believed everything would be alright as I had never felt ill, had indulged in many sports through life. Recently, however, I had been reduced from the more energetic sports of cricket, football, tennis, badminton and squash to the game of golf.

The colonoscopy procedure was painless and I was able to monitor the screen as the radiographer explained the journey of the camera along the colon. He then said: "Can you see that?" pointing to what appeared as a large black mass. A nurse was sitting by my side holding my hand and as the

radiographer explained that this was a large tumour she tightened her grip on my hand. I remember asking why it had not shown two years earlier and of course he was unable to say.

The tumour was cancerous and aggressive and so events then moved very quickly. A week or so later I was admitted to Castle Hill Hospital, Cottingham for surgery by colorectal surgeon, Mr JD Armitage. In a way, I could not believe this was happening to me. At the colonoscopy, the radiographer did say that I was very lucky that the tumour had been found that day. I have heard since that some people just throw away these postal tests. My case shows that you must always do the test and send it in because what might have happened if I had not does not bear thinking about.

The operation to remove the cancer and re-join the bowel was carried out on 26 June 2011. On the evening of the sixth post-op day my wife and son, Neil, visited and I felt reasonably well. After they left, I can remember nothing further as I must have blacked out. When I did open my eyes all I saw was a sea of faces looking at me. People were moving and talking and obviously something was wrong, very seriously wrong. I remember one of the staff saying I was being taken for emergency surgery.

I later learned that the first operation had resulted in a bad leakage and that peritonitis had set in. Apparently, they had 40 minutes to get me into surgery to save my life. I remember a nurse being told to arrange a bed in ICU. Well the bed in ICU was required. I survived the operation with grateful thanks to Mr Armitage and his wonderful team yet again.

For the next few weeks in Castle Hill Hospital I received intensive nursing. I was on a high level of morphine to combat the severe pain. Unfortunately, this medication made me see and hear things that were not really happening and I committed these to paper. When my youngest son visited I gave him these notes and made him vow to sort these people out. He obviously viewed me with suspicion but said he would! As I recovered I continued keeping daily notes which I found helped me to understand what I was going through and to make some sense of the medical procedures.

not out!

I was eventually released a few stones lighter and with my permanent stoma. It does not have a pet name; I prefer to address it how it is behaving at the time! While at home I continued writing my diaries. With the help of my stoma nurse, Amanda, from Scarborough General Hospital I have slowly accepted my stoma and learned to manage my daily life.

My two operations did not completely remove the cancer. It had been diagnosed as aggressive; parts of the colon wall and two lymph nodes remaining were of concern to my consultant. My oncologist decided that chemo was required. I voluntarily signed up for a clinical trial, Short Course Oncology Therapy (SCOT) in which patients would be given chemotherapy for either three or six months and then followed up for a seven-year period, so the study is still ongoing. I was allocated to the group that would receive chemotherapy for six months.

I commenced cycle 1 on 29 September 2011. Day 1 was allocated to intravenous infusions at the hospital and the rest of the week to tablets. Week 2 and 3 were the same, with week 4 completely free. As each monthly cycle progressed the chemo was making me physically worse, suffering from diarrhoea and sickness. I thought, well the cancer is not going to get me, but the chemo is!

At my lowest point, I wrote in my diary:

SCREAM and then jump into the sea! But maybe not. I will keep battling as I was given 'not out' during surgery and it would be a shame to 'give my wicket up' now, especially when I'm on 72 and could get my 100, but the weather is getting very choppy and the pitch is getting very unpredictable, some bounces and a lot of low balls...

...I am stopping the tablets now... what overall effect it will have on the cancer I don't know and right at the moment I don't care. I just want some pain-free quality time, this is depressing me big time...

For the depression, I was referred to the Oncology Health Centre at Castle Hill Hospital for treatment. The nurse, Mrs Julie Bateman, was outstanding in her approach

to me and I truly thank her. Eventually, I decided that I was taking no more chemo, no matter what the consequences. I duly informed my oncologist and the cancer research nurse who both acknowledged my decision.

This and subsequent years were difficult for me and the family and, in many respects, this continues to this day. I have slowly accepted to manage my daily life, although it is not easy as I have constant pain of various degrees. Also, as a result of disruption to the stomach and digestive system during surgery, I have dumping syndrome which occurs about 30 minutes after meals. When this happens my body just shuts down and I have to go to bed. Needless to say, I leave having a meal until evening so that I can lead as normal a life as possible through the day.

I was only part of the backing group and that my son in law was the LEAD singer. Much laughter.

I am now approaching six years post diagnosis. Further tests revealed that I was in the clear and have remained so. My grateful thanks extend to Mr Armitage and his excellent team and all the staff at Castle Hill Hospital and also in the Chemotherapy Department at Scarborough General Hospital. Finally, I could not have made it without the love, understanding and caring of my wife, Doreen, our four children and our nine grandchildren. They have all been part of my journey so far, in serious times and very much in funny and lighter times, and they all keep me looking forward to the next day.

Gilbert



Gilbert's wife, Doreen, with their nine grandchildren

Enough I hear you all cry! Tell us something that will bring a smile to our faces. Well how about this? My son in law who also underwent surgery for colon cancer two years ago and I were both at a family dinner. He also has a permanent stoma. After a while his stoma started to sing and mine followed suit. Now, as we all colostomates know, our stoma has a mind of its own and we have no control over it. Someone in the dinner party said that was good. I hastily reminded her that

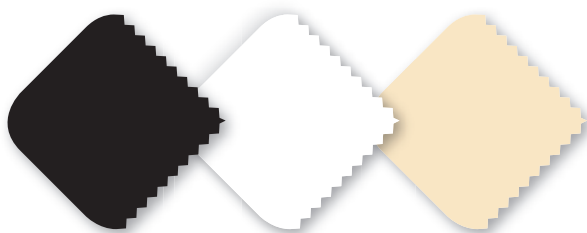
Medical Terms Explained

Dumping syndrome is caused when food, particularly sugary and starchy food, moves too quickly from the stomach into the small intestine. Symptoms include feeling faint, sweating, palpitations, nausea, indigestion, bloating and a need to lie down. People who have had stomach surgery are more likely to develop dumping syndrome.



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Update on stoma care products and services

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

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Not just once but twice



Lyn with her partner, Bill, and her niece, Natasha.

My story started in late 2014 when I was 54. Following a routine breast screening I was given a biopsy. Then on Christmas Eve I received an appointment to see a consultant surgeon. My family tried to reassure me but I knew what this meant. I was right; it was confirmed on New Year's Eve that I had breast cancer. I had a lumpectomy, then three weeks of radiotherapy.

Getting the 'All Clear' was great, but the trauma of it all left me in deep shock. I was diagnosed with deep depression. I scored so badly on an assessment that the doctor asked me if I had suicidal thoughts. I did not as I am generally a happy person; I have a lovely partner, a great job, and own my own home. I was off work for some months but eventually returned to my job in the sales office of a large engineering distributor in the West Midlands. After just eight days back at work, a bowel screening test showed some abnormality and I was called back for a sigmoidoscopy. I heard the radiographer say: "There's a large tumour."

You can imagine my horror after my previous cancer scare. I was in such a state that I couldn't return to work. A colonoscopy showed a second tumour in another part of the bowel that also turned out to be malignant. I'd had no symptoms at all prior to this happening.

I had my operation in September 2015. The surgeon was unsure whether I would need to have a stoma but explained that if I did they would try to make it temporary. When I woke up I found it difficult to hear what people were saying. Words cannot describe my feelings at this point. It was bad enough having the operation, but being deaf was terrible; the surgeon could not explain how it had happened. Not only that, but my stoma was permanent. I was in hospital for many weeks getting over all this. I remember the first time the stoma nurse showed me how to change my bag. I had very little strength and found it very difficult to do myself. Eventually I went home which was a big relief, but I still needed to have 30 chemotherapy treatments.

The chemotherapy started in November 2015 but had to be stopped in December due to breathlessness and loss of appetite. I was determined, however, to get through it and get the whole thing finished. I rested and tried to eat little and often as meals made me sick. Eventually when I was less breathless and had gained weight the chemo was started again. I finished the chemo at the end of July 2016. When it ends, you get a slight feeling of relief and happiness. A CT scan in September gave me the 'All Clear' but I do still worry that the cancer will come back.

When you first have a stoma, it takes a long time to get used to it. I use a drainable bag that I open and empty into the toilet. I change the bag once a day. At first I made mistakes, especially at night which was upsetting. However, you soon get to know what you have done wrong, so it doesn't happen again. I haven't had any leaks for many months now. At one time my skin was getting sore. This was because my stoma had changed shape since surgery. The stoma nurses changed the type of bag and the size of the hole in the flange. Since then I have had minimal problems which is encouraging. Someone I spoke to at the time of diagnosis said: "It's doable." It is, you just have to try and make yourself strong. It has not ruined my life. You just cannot do anything about what has happened and just have to get on with it.

I think being deaf is worse than a stoma. I now use a hearing aid. My job was a full-time sales administrator which involved a considerable amount of time on the telephone. When I returned to work, my manager tried to arrange for the phone to be adapted so I could use it. This was not possible so my job was changed and now I only use e-mail and fax and this works. You do need support and I am proud to say that my work colleagues were a huge support for me. Their visits, e-mails and texts, some from people I hardly knew, meant so much to me. The human resource director kept in touch throughout and also visited me and sent gifts. I owe so much to the company I work for which spurred me on to return to work. I am now looking forward to moving on and would like to help other people with cancer.

Lyn Barnes

Medical Terms Explained

- A sigmoidoscopy is a procedure which examines the last part of the large bowel (sigmoid colon and rectum).
- A colonoscopy is a procedure which examines the whole of the large bowel.
- Both tests are carried out using an endoscope. This is a narrow flexible tube; at one end is a light and a camera that relays images of the lining of the bowel to a monitor.



Sinead is the author of the paper, **Protecting peristomal skin: a guide to conditions and treatments**, published in the *Skills in Practice* series for nurses in *Gastrointestinal Nursing* (September 2016 Vol 14 No 7). She kindly agreed to write an article on the same topic for *Tidings*.

Peristomal Skin Protection and Treatments

Sinéad Kelly O'Flynn Dip Nurs. G Dip G.I., Msc Adv Practice
Clinical Research Nurse, Cork, Ireland

Healthy skin around the stoma (peristomal skin) is essential so that your pouch adheres correctly to the skin, minimising any discomfort or leaks. The skin is slightly acidic and can get damaged when it comes into contact with faeces or urine causing contact dermatitis. Good stoma management prevents peristomal skin soreness.



Healthy Peristomal Skin

Peristomal skin conditions occur predominantly straight after surgery or within the first year but can also occur at any time. These conditions can be treated and corrected with the use of different appliances and additional products. It is important to consult a stoma care nurse as they are aware of all products which might be suitable. Some products i.e. convex appliances may need to be prescribed and/or may need reviewing or continuous observation.

Table 1. Peristomal skin complications and solutions

Creases and/or dips	<ul style="list-style-type: none"> • Level the skin with a seal or paste
Leak with parastomal hernia	<ul style="list-style-type: none"> • Level the skin • Use a flexible convex appliance • Use a hernia support garment
Leak with retracted stoma	<ul style="list-style-type: none"> • Use a convex appliance
Skin stripping	<ul style="list-style-type: none"> • Use an adhesive remover spray or wipes
Folliculitis	<ul style="list-style-type: none"> • Use an adhesive remover spray or wipes • Shave the peristomal area regularly
Sore skin	<ul style="list-style-type: none"> • Check the size of the aperture in the flange and resize if necessary • Use stoma protective powder, barrier film or cream
Wet skin preventing the bag from sticking	<ul style="list-style-type: none"> • Use a specialist powder to dry the area and remove excess powder before applying a bag • Use a hairdryer (cool setting and kept at a safe distance from the stoma) to dry the skin

Peristomal Skin Complications and Causes

Most Common

- ❖ Contact dermatitis often occurs due to faecal/urinary leakage which often results through ill-fitting appliances, a retracted stoma, a parastomal hernia or skin creases or folds.



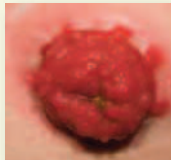
Contact Dermatitis
(Peristomal Skin Excoriation)

- ❖ Peristomal skin conditions can also occur if the hole in the flange is cut too large, patched up after a leak or left on for longer than the manufacturer recommends.
- ❖ Skin stripping can be the result of physically pulling the pouch off the skin. This can cause the removal of the outer layer of skin, causing over hydration which can lead to wet stoma skin, which in turn affects the adherence of your pouch, resulting in leakage.
- ❖ Folliculitis, itchy painful skin, can be caused by excessive or rough shaving and rough appliance removal.



Folliculitis

- ❖ Overgranulation (granulomas) usually occurs where the stoma and skin join. It is caused by irritation from the flange or faeces.



Peristomal Overgranulation
(Granulomas)

Less Common

- ❖ Candida infection, characterised by symptoms of very sore skin, itching or white pustules.
- ❖ Mucocutaneous separation, where the stoma becomes separated from the skin. This usually only occurs in the early days/weeks after surgery due to infection, tension or lack of blood supply to the tissue.
- ❖ Peristomal pyoderma gangrenosum, ulcerative, pustular lesions/craters which cause extreme pain.



Mucocutaneous Separation



Peristomal Pyoderma Gangrenosum

Table 2. Products for preventing and treating peristomal skin conditions

Product	Use
Barrier cream	<ul style="list-style-type: none"> • Moisturises dry skin • Prevents skin excoriation (abrasion)
Barrier spray	<ul style="list-style-type: none"> • Creates a protective layer on the skin
Calamine lotion	<ul style="list-style-type: none"> • Soothes sensitive or itchy skin • Aids pouch adherence
Convexity appliances (check with your stoma care nurse before using this type of appliance)	<ul style="list-style-type: none"> • Reduce leaks from poorly-spouted stomas by pushing into the abdominal wall so that the stoma sits further into the bag
Flange extenders (Not to be used regularly to stop leaks as the stoma output can collect under the flange and cause sore skin)	<ul style="list-style-type: none"> • Increase the adhesive area
Hairdryer (use cool setting)	<ul style="list-style-type: none"> • Dries moist or wet skin
Hydrocolloid <ul style="list-style-type: none"> – flange on appliances – wafers and skin barriers 	<ul style="list-style-type: none"> • Absorb moisture and protect the skin
Paste and Seals (Barrier rings)	<ul style="list-style-type: none"> • Fill creases and dips to aid adhesion • Reduce leaks and protect the skin
Silicone adhesive remover	<ul style="list-style-type: none"> • Removes the bond between the flange and the skin without leaving residue • Minimises skin stripping and trauma to fragile, damaged skin
Specialist powder	<ul style="list-style-type: none"> • Dries moist skin • Treats broken, wet or oozing skin with a protective layer • Aids adhesion
Stoma collar	<ul style="list-style-type: none"> • Forms a leak-proof barrier around the stoma

Key points

To prevent the skin around the stoma becoming sore:

- ❖ Remove a bag slowly and carefully to avoid skin-stripping. An adhesive remover can aid removal.
- ❖ Check that the hole in the flange is the correct size to prevent the flange rubbing on the stoma while still ensuring that the stoma output does not come into contact with the skin.
- ❖ Leakage beneath the flange can go unnoticed when using flange extenders. They should only be used occasionally for extra security and reassurance.

If you have an ongoing skin problem that is not resolving:

- ❖ Always contact your stoma nurse for a review so that your skin condition can be assessed and appropriate treatment prescribed.

It is also advisable to have a stoma nurse review your stoma once a year to safeguard against complications.



– by Linda

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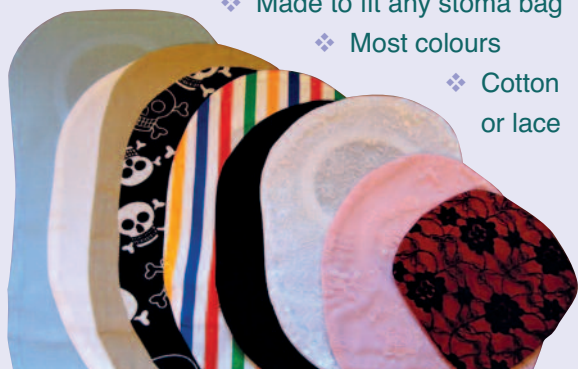
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The cost of sending unneeded supplies to Stoma Aid can be reduced by using Hermes which has over 4,500 collection points across the UK. Prices start from as little as **£2.70** per parcel and more details can be found about the locations of their Parcel Shops on their website below (or by telephoning the **Colostomy UK** office with your postcode):
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**Stoma Aid will accept the following:
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- Two piece bags (must include matching baseplate/flange)

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- Absorbent gels
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- Frames and flange extenders
- Night/drain bags
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Stoma Aid cannot accept syringes, deodorants, prescription medications or drugs of any kind.

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

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

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

Dear Nurse

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



Due to lack of space we were unable to include the following question and answer in the last issue of *Tidings*.

Q: *Eleven years ago, at the age of 60, I was diagnosed with rectal cancer. The treatment I received included chemotherapy, radiotherapy and surgery resulting in a colostomy. After the initial problems of getting used to a colostomy and all that it entails, everything was straightforward for a couple of years until the following occurrence. Spasmodic pains in my lower abdomen for several hours going right down into my groin.*

Later the pains move to just below my navel, down the lower right side, spasmodic and distending my abdomen with pressure. Again, this could continue for several hours up to 24 or even more. These pains are very strong and leave me unable to stay in bed or sit down for long. Eventually I start to feel nauseous but it still takes a long while before I can vomit. Over the next 12 hours I can be sick three or four more times. Later I start to feel more normal and my colostomy bag will fill considerably. I feel sore and a bit shaky for a couple of days or so afterwards.

I have had this occurrence about seven times in eight years, the most recent about a week ago. On three occasions, I have been taken to A & E and X-rayed. After the first X-ray, I was told that my problem was due to adhesion of my bowel, causing a temporary obstruction.

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.

On the other occasions, I was told constipation was the problem.

My GP has told me to take laxatives when the symptoms first appear but a) I just don't have the appetite to drink much and b) it eventually comes back up. I am wondering if you had heard of like experiences from other colostomates.

I am quite fit and active. Mountain biking and walking are among my interests.

A: This sounds like it could be intermittent obstruction caused by the adhesions and if it is a regular, debilitating occurrence it may be worth you seeing your surgeon again to see if there is anything they can offer surgically. The problem is that if it is due to adhesions then it may continue to occur and you may find the frequency increases and you may need to be admitted to hospital so that they can investigate this

to identify the cause and possibly offer a treatment.

So that the reader who asked the question wouldn't have to wait too long, we e-mailed him Julie's answer. He sent the following reply:

I had an appointment with my stoma care nurse and after hearing my explanation of the problem her view was very similar to Nurse Julie Rust's. She thinks the problem could be blockage caused by scar tissue, adhesions or misalignment of the bowel.

Her advice was to follow the NHS recommendations for food eaten during the first six weeks following a bowel operation and, if I get the occurrence again, she also thought I should go to my GP and ask to be referred to my surgeon.

Julie replies:

I am glad that you have managed to see your local stoma care nurse and that she has been able to give you advice with regards to diet and also what to do if you have a further obstruction.

The reason for eating a diet similar to that advised straight after surgery is that it tends to be more easily digestible. Immediately following surgery, the bowels can be erratic and therefore we advise foods which do not cause too much of a problem and also advise smaller more frequent meals. This can sometimes help with intermittent obstructions.

CONTINUED ON PAGE 34, COLUMN 1

CONTINUED FROM PAGE 33, COLUMN 3

Q: *Six years post resection of the anus and a permanent stoma, I have only one problem. At the site where the anus was removed the wound has never healed, despite attempts to surgically scarify out degraded tissue and even vacuum therapy. The inch-long opening into the dark world of my body remains defiantly open and continuously weeping exudate and blood.*

Each day I have to gently pack it with a long ribbon infused with silver and then attach dressings; on two occasions infections from this opening have seen me back in hospital with sepsis. Initially I had to attend my doctor's surgery for this procedure, but now manage it myself.

Despite this hindrance I have been able to remain active and recently walked to the top of Snowden, Scafell Pyke and Ben Nevis! However, I'm getting fed up with the malodorous discharge.

My surgeon doesn't seem interested at all. His take is that the radiation so damaged the cells and the open internal space left after the major surgery means the sinus will never be resolvable.

My questions are:

- 1. Is there any avenue I could look at such as plastic surgery or am I destined to forever pack and dress?*
- 2. Can I get away with packing less frequently and avoid infections?*

I would like to hear from anybody else managing this extra hole!

A: This is a difficult question to answer as I do not have access to your medical records. Radiation prior to surgery can cause damage to the tissues and delay healing. You appear to be managing the problem as well as can be expected and do not seem to let it stop you being active.

However, I can understand your frustration and I wonder if a frank discussion with the consultant surgeon,

perhaps with your stoma nurse present as an advocate to try to explain your problems and concerns, would help. They may be able to answer your question about any other alternatives such as referral to another surgeon or possibly a plastic surgeon, if that is feasible.

It may be worth your GP referring you to a specialist tissue viability nurse, either in the community or in the hospital setting to see if there are any other options for redressing/packing the wound which may help to reduce the discharge and the odour.

I hope you can find a solution to your problem and continue with your active lifestyle. All the best

Q: *I acquired my stoma in May 2016 at the age of 72, along with a lifetime of TPN, as a result of a blockage in my small bowel. After surviving life-saving surgery, I only had 10cm of small bowel left to form the stoma, so it surfaced via the shortest route, which is where my belly button used to be and where my ongoing problem began.*

The first hurdle I have to overcome is to provide a flat surface on which to stick my pouch by bridging three crevices the deepest of which is 22mm wide and 50mm long. To date I have managed to get it to last 24 hours before leaking. Before I proceed any further it is important to inform you I have the support of a very good stoma care nurse who points me in various directions and on occasions gets as frustrated as me.

As a result of the constant seal failure the skin in the area around the stoma is very sore and bleeds and the application of any ointment increases the failure rate of the pouch. I have gone as far as removing my pouch, applying cream

and leaving the stoma uncovered for extended periods hoping to get some relief but this is all very messy.

I've passed the point where I thought it's all been a nightmare and when I wake up everything will be back to normal and the 'Why Me' syndrome, so what I need now is your input to help me move on. I have already enlisted the support of the local stoma group whose experiences have helped me to get over myself and be positive. Now I need a wider audience to sort out my soreness and stop the leaks.

A: This is very difficult to resolve as your stoma care nurse is finding. There are several issues. Firstly, if the skin crevices around the stoma, secondly there is the issue of excoriated skin due to the constant leakage and thirdly the output is probably very liquid and prolific. These all compound the issue of gaining a good seal for the appliance to the skin and it is difficult to offer answers as I do not know what your stoma care nurse has tried.

There are many products on the market including convexed pouches of different depths and strengths and also high-output pouches to try to manage this sort of situation. There are also many skin preparations such as barrier wipes, seals, strip pastes, adhesive sprays and powders, but your stoma nurse may have tried differing combinations of these.

We have had some success with ilex skin protectant applied to sore skin and covered with a seal to try to solve this problem and I am not sure if your stoma care nurse has tried this.

I hope that you manage to reach a solution that works for you with the help of your stoma nurse, who you obviously have a good relationship with. All the best.

Medical Terms Explained

TPN stands for Total Parenteral Nutrition. This is a means of supplying all the daily nutritional requirements of patients who have a short or malfunctioning small bowel. It is given intravenously (administered into a vein) via a special catheter. This can take place in hospital or at home. The concentrated solutions are manufactured for individuals, dependent on their needs.

A reader's suggestion:

On reading a letter to Dear Nurse (Tidings Issue 46 page 40) I would like to offer some possible help to the lady concerned.

In 2010 I was diagnosed with anal cancer and had an Abdominoperineal Resection (APeR). Within the first few weeks I developed a perineal hernia – felt like the size of a plum – protruding from where my anus/rectum had been. It was most uncomfortable at best but painful most of the time, especially when seated.

It was decided that, for safety's sake, I had to wait six months before I could have the hernia removed! Whilst this made sense – some healing internally had to take place before operating again – it was extremely distressing. The horrible physical and mental unease forced me to restrict my outings, car trips, bus journeys, train journeys, sitting in restaurants, to a couple hours.

My sisters and I had already booked tickets for The Ideal Home Exhibition and whilst there we passed a stand that had a line of seats laid out on a bench and we all sat down for the novelty of it. WOW, it was so comfortable for me, I could not believe it! The seat is called Backjoy Posture Plus. It is light and portable, more a moulded frame to keep one's seated weight contained and not enabling buttock spreading and thence sitting on the offending lump. It solved all my discomfort problems.

Even after the hernia correction operation I still had a lot of tightness and discomfort and I continue to this day, seven years later, to carry the seat everywhere in a light canvas bag for trains, restaurants, cinemas etc and have another permanently in my car. I even take it with me to the gym to put on apparatus and use it for floor exercises whilst doing yoga. I would thoroughly recommend looking at their website www.BACKJOY.com – it changed my life. I think you can also buy them on Amazon.

The standing discomfort I have tried to switch off from but did find that losing a stone and returning to a healthy weight for my height helped lots with 'anus' discomfort and stoma management.

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

E-mail:
editor@ColostomyUK.org

or write to:
The Editor
Colostomy UK
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.

Julie replies:

I have not heard of or seen this but if it has proved successful for one person then that is good and sharing it may help others. Always remember though that what can be beneficial for one individual may not suit everyone and in-depth research should be undertaken before purchasing.

Photo ID Card

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

To apply for a Photo ID card, please complete the form opposite and return it to the **Colostomy UK** for processing with the various enclosures listed below:

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

***Note:** Credit card payments can be taken over the telephone if preferred, ensure the above are sent in the post in advance.

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

Allow 10–14 days for delivery.

Previously issued cards will still be valid.

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

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

(If you have any queries or would like to make a credit card payment, please contact the admin team at the **Colostomy UK** office via the following methods: Telephone: **0118 939 1537** or Email: info@ColostomyUK.org)

National Key Scheme - Key and photo ID card purchase

Title: _____

Name: _____

Address: _____

Postcode: _____

Tel: _____

Email: _____

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

Signature of self or carer: _____

Date: ____/____/2017



Please **tick** as appropriate:

- ☐ I would like to receive a **key** for a charge of **£3.50** (including postage and packing).
- ☐ I would also like to receive a **photo ID** card for a charge of **£6.50** (including postage and packing) and enclose a passport photograph.

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

For payment by credit card, send your documents in the post with a contact telephone number, we will then call you to take a card payment when received.

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 Editor

I recently returned from a stoma-bag-incident-free trip to Australia, and have booked to go again in September. I'd like to share a few tips, particularly if you are going long-haul by air.

Take double of everything that you think you need, and all in hand luggage in case hold luggage goes astray. (I also keep a small stash of everything with my relatives in Australia.) Remove stoma bags from their boxes to save space. If you have to take any prescribed medication keep them in hand luggage too, with a copy of your prescription.

To change in an emergency, I carry spare sets of two or three bags, together with wipes and adhesive remover. I put these together with my RADAR key in a plastic box that I keep in my backpack which I also use when out and about in Australia (and here at home too!)

All aerosols need to be declared in the proper plastic bag at security; I include a copy of my prescription to back up my reason for having them. In Dubai, adhesive remover sprays were queried as they can be inflammable, but were accepted. I have since discovered that adhesive remover is available as wipes which gets around any problems at airport security.

On the flight, I wear a battered old pair of slip-on leather deck shoes so they can be kicked off easily at security or on the plane. I put on my flight socks at home but only pull them up after boarding the plane. I also wear track suit bottoms to travel in so no belts to take off and put back on at security, also no trouser waistband to press on and maybe dislodge stoma bag when being seated for a long time. I put cash in separate purses,

one for each currency if necessary, to save scrabbling around in the plastic tray after security scanning.

On long-haul flights get up and walk about every hour or so, drink water in the main – but wine is nice too!

Yours
Roger

Dear Editor

Last November, 13 months after my double stomas (a colostomy and a urostomy) arrived following endometrial cancer in my pelvic area, we decided to just go on some of the holidays we had always wanted to take. We spent five weeks in Australia and visited family and friends and included a cruise to Fiji and New Caledonia.

This was something of a test for me particularly the four long flights with two days in Hong Kong and Singapore. We were 'cattle class' but I still managed to use my night pee bag during the flights which was a great help as it avoided the frequent trips to the loo. I used the blanket to keep it discreet and chose a window seat where possible. My husband generously took the mid seat although he previously always took an aisle seat for his long legs. He also took my pee bag in a plastic bag to the toilet to empty it at the end of the flights.

However, I had not at that time read your travel tips in the winter 2017 issue of *Tidings* and had various 100ml adhesive remover sprays in my hand luggage and handbag. These were not picked up through four out of the five security checks, but on the domestic flight out of Sydney they were more rigorous and our two carry-on bags and my handbag went through

several searches before the sprays and my asthma inhaler were all located! Apparently, they were worried that these could be pepper sprays!

The other interesting airport check was going through the security screen with two stoma pouches. I told the staff in advance each time and had no problems at all until leaving Sydney for Singapore when I was randomly selected to go through a full body scanning booth. Again, I mentioned I had stomas. The attendant asked to see and fortunately I was wearing a skirt so could just lower the waistband. She then said to stand in the appropriate position for the screen. I saw the picture and it had yellow splodges across my midriff. She then asked me to show her the whole bags. I suppose I could have demanded a private room for this but it seemed easier if embarrassing to just lower my waistband even lower so she could see my two pouches, and their contents in more detail. Boy, was I glad I was wearing a skirt; I had chosen it to allow me to use my night bag for peeing more easily.

We had a fantastic holiday. It wasn't without its trying times as my urostomy bag leaked at inconvenient moments. Also, wearing two sets of pants (the second pair being support pants) was very hot in temperatures of 29–33°C but we didn't let it stop us doing what we wanted. I only swam when I was able to change my wet pouches easily but did enjoy several swims. Being with friends, who knew my position and were very relaxed and considerate, helped enormously.

Regards
Kathy

Readers' writes

Dear Editor

I had my colostomy in November 2015 and I am coping fairly well. However, I do have a problem which I hope someone can offer me advice on, and that is wind. I never thought I was a 'windy' person but it has become quite a problem, and it is confounded by the fact that I have quite a large parastomal hernia. My bag sits in my left groin so when I sit in a low chair or lean forward to get out of the chair it gets a bit squashed. Add in the hernia and wind trapped in the bag and I worry it will come adrift. It has done once or twice.

I use drainable bags. I can't understand why anyone would use closed bags, because I vent mine two or three times a day and I would hate to have to change a closed bag every time. I experimented with various makes until I settled on Hollister's because these bags gave me the best adhesion, then I read in a reader's letter in the last edition of the magazine that Hollister's filters are not very effective, a view that I was coming around to all on my own! Sometimes the filter will vent suddenly, giving off an unpleasant smell, which makes me think I have sprung a leak.

I have tried cutting down on 'windy' vegetables, but I like my five a day, and I take charcoal tablets which help, but they are not a cure – has anyone any suggestions, please?

Yours sincerely
BB

Editor's Note: A few suggestions for dealing with wind can be found in Hints and Tips for new ostomates on Page 14.

Dear Editor

Regarding the letter in the Spring issue from Simon Jones about his colonoscopy.

My first colonoscopy was when the cancer was discovered which led to my having colorectal surgery and a permanent colostomy in 2012. I used Moviprep then and when I had a follow up colonoscopy in 2016. I really wasn't looking forward to it at all for several reasons. The thought of

using the purge with a bag in-situ made me anxious and I had found the first colonoscopy to be the most painful experience ever. I had resolved the second time to be sedated. They had said previously that I might not remember the procedure whilst under sedation but actually that was not the case and everything went well.

In preparation for the colonoscopy, which was an afternoon appointment (1pm), there were guidelines regarding what to eat the day or two before. The instructions for the cleansing said I had to take the one sachet at about 7pm, over an hour, the night before. The purging started about 8pm, I just sat in the bathroom and it was finished by 10pm.

The second preparation I had to take at 6am the following morning. This was the one that was a little more difficult to take not only because now that I am retired I rarely see 6am but because the body doesn't want to take the salts in the drink. Nevertheless, over an hour I managed to drink the preparation and again by about 10am it was done and dusted. No problem with stoma or bag, but I should mention that although I have a colostomy I use a drainable bag. Afterwards, I did wonder what on earth I had been worried about.

I notice on the instruction for the preparation (which I have kept) that the course of treatment can be taken either as divided doses (evening and morning) or single doses as described in the leaflet. The additional information I had regarding Moviprep was that I should take the two doses separately evening and morning.

I would query the instructions that Simon was given with regard to the Moviprep inasmuch as they seem very intense. No wonder he felt exhausted – his body really was purged in the extreme and I think that bag or no bag this was going to be a really difficult few hours. Was this necessary since there seems to be an alternative?

I hope this letter is of some comfort to any others getting ready for their colonoscopy.

My advice is always be ready to ask questions of the health professionals and to ask for the divided doses which, in the light of Simon's experience, seem to do the job without undue stress to the body.

Regards
Margaret Priest

Dear Editor

Both my wife and myself have stoma bags; I have an ileostomy, she has a colostomy.

My wife has been many times to seek help with the life-changing pain in the rectal stump. Her monthly repeat prescriptions include incredible amounts of pain relief medication.

I showed her the remarkable article on rectal discomfort by Andrew Bird and we hotfooted it to a GP to show him too, and ask his opinion. He prescribed suppositories and yesterday my wife managed to reduce her painkillers to survive the day. Only time will tell but she felt so encouraged by this article, suddenly aware that she was not on her own.

The whole magazine is oxygen for the brain to us and all readers I am sure. Thanks and thanks again for all your team's efforts.

Kind regards,
Bruce Dibben

Dear Editor

In April, I prepared for a two-week cruise with my wife, Beth, to Vietnam, Korea, Hong Kong and China, with my usual irrigation kit, but with extra pouches, 'just in case'. Being blessed with very regular habits I really wasn't too worried. How wrong could I be?

On boarding the Royal Caribbean Ovation of the Seas, 4,500 berth ship, in Singapore, and just having gone through the checking in process, which included a signed statement that I wasn't suffering from diarrhoea, it hit me. No nausea whatsoever, but all too evident discharge.

CONTINUED ON PAGE 38, COLUMN 1

Readers' writes

CONTINUED FROM PAGE 37, COLUMN 3

That first day I used six pouches and the condition showed no signs of finishing. Four pouches on the second day and a growing panic that I would use up my supplies. No spares in the ship's excellent medical suite, nor at any pharmacy on our shore stops in Asia.

Time for ingenuity. I fell back on using an irrigation sleeve as a pouch, flushed through and folded up for the day. Easily drainable and used on the days at sea, saving my usual disposable pouches for shore excursions and night time when the sleeve wasn't so efficient. Wind was better managed during daytime with a sleeve with no filter. Incidentally, for a better seal, I use a large food-bag clip rather than the dainty orange pegs supplied by Dansac.

Irrigation on a cruise presents no real difficulty, although I always travel with string to secure the water bag. On a ship with a compact, en-suite bathroom the shower-unit frame provides a hanging point, and there are plenty of surfaces to spread the ancillaries.

In future, I will take plenty of disposable bags but also a few large drainables.

Regards,
Luis Castillo

Dear Editor

Two years ago, I had a colostomy due to colitis and diverticulitis. As I had medical insurance I had it done in a private hospital, which sounded perfect: my own room, even a stoma nurse I was told would visit me every day. The operation didn't bother me as I was looking forward

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.

to getting rid of the pain. I saw a stoma nurse at a NHS hospital the week before my operation. She showed me a bag, and answered my questions.

After my operation I felt very isolated, in a room on my own with no one to talk to. I had this bag laying on my tummy and wondered what happens now. When I asked the nurses, I was so surprised that they seemed to have little knowledge about stomas, but I had the stoma nurse coming, or so I thought; she never did, not until half hour before I went home!

When my bag filled it started to leak. I rang bell, but had to wait an hour and half before a nurse came in to change it and I saw my stoma for the first time. The nurse never spoke only to say that some people can't even look at their stoma for ages. Well, I wasn't one of them, and came into hospital feeling confident. My skin was sore so she left me without a bag and went to find what I know now to be antiseptic powder and, well, I'll leave it to your imagination what was happening.

In the end, it was my husband who showed me how to put on a colostomy bag. He googled YouTube videos and we did it together. I suppose what I'm really getting at is that in the NHS you have a stoma ward with stoma nurses and people who are in the same position. It wasn't until I had blockages and was admitted to a stoma ward in an NHS hospital that I was able to talk to other people like me with stomas, and there were no embarrassing moments. A room with a view, and your own bathroom, wasn't worth the way I was made to feel. I would say that even if you have private insurance, it's important to be amongst people who are going through the same thing on a ward with nurses trained to care for people with stomas.

Lesley Phillips

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?

Colostomy UK 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@ColostomyUK.org

or a letter to:

**The Editor
Colostomy UK
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 **Colostomy UK** 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.

For more information about the issues discussed in these letters i.e. travel, colostomy irrigation, colonoscopy etc. contact **Colostomy UK** 24-hour free helpline **0800 328 4257** or visit **www.ColostomyUK.org**

“

let's talk!

Nottingham QMC Stoma Support Group

”

...about stomas,
colostomies, ileostomies & urostomies

We are not sure exactly when the support group at Nottingham Queens Medical Centre (QMC) first met, but it's at least 30 years ago. In all that time, apart from a couple of times when the clinic space wasn't available, we've met every third Saturday of the month. Hospital stoma care nurses join us when they are able.

Andrew Bird took up the post of lead stoma care nurse specialist at QMC in March 2015. He attends most of our meetings or if he is working that weekend makes sure he pops in to see us. He is keen to point out that a support group is just that, somewhere that people who have stomas can support each other and socialise; it is not a clinic. He is, however, happy to talk to anyone who comes along and listen to their concerns and, if necessary, will make an appointment for them to see him or one of the other nurses. His team includes Lisa White and Kate Wilson who drop in when they are on duty on a Saturday.

At one of our meetings earlier this year Andrew gave a presentation on stoma care and later in the year he will be holding a Question & Answer session. Miss Catherine Walter, a colorectal surgeon who also works at QMC, spoke about stomas from a surgeon's point of view. Every month a representative from a different manufacturer or supplier comes along to keep us up to date with new stoma products and services.



Andrew Bird, Lead Stoma Care Nurse Specialist, giving a short presentation to the group (May 2017).

But not all our topics are medical. In July, we had a taster session of Tai Chi, a gentle and relaxing form of exercise, very good for people with stomas as it strengthens core muscles. Last year we had a talk about Nottingham: Past and Present and another about a member's travels overseas. And, of course, there is always time for a chat and a cuppa. In January, we always celebrate the New Year with a party.

Everyone with any type of stoma, relatives, friends and carers will be made very welcome. It may be that you have only recently had a stoma, are a bit anxious about going out, and just want to come along once for a bit of support. Or maybe when you realise that you are not alone and there are other people who feel the same as you, you will want to join us again. We are always there in Clinic 2, Queens Medical Centre, Derby Road, Nottingham NG7 2UH on the 3rd Saturday of the month from 10am until 12noon.

Come along...

The group meets on the third
Saturday of every month.
10am-12noon at the QMC.

Dates for next three months:

Saturday 21 October 2017
Saturday 18 November 2017
Saturday 16 December 2017

More info...

For further information
please contact:

Rosemary Brierley
01159826691 rosemarybrierley@gmail.com
Mike Lucas
01158081356 lucasmichael1@sky.com
Andrew Bird
01159249924 ext. 64197 andrewbird.stomacarenurse@yahoo.com

News from Local Support groups



Recently Carla Wright established a stoma support group that meets monthly in Chesham, Buckinghamshire. You may feel stomas are a very private and personal matter. You now no longer have to feel alone. Whatever your age or circumstances this group provides support; you can meet and talk with other people who also feel isolated, not being able to talk openly about their experiences.

Apart from the social aspects of getting together there are the opportunities of meeting stoma nurses and suppliers of stoma products to give comfort and security.

Come and join us for a friendly chat and coffee

Chesham Kings Church Office, Unit 11 Chess Business Park, Moor Road, Chesham, 5HP 1SD

The group meets once a month on a Monday from 10.30am to 12.30pm

Dates for the next meetings:

Monday 30 October 2017

Monday 27 November 2017

For more information contact:

Carla 07846 354918 carla_wright@sky.com

Les 01494 785076 les.lee@zen.co.uk

Northampton Ostomy Support Group

Trish writes:

After an emergency colectomy, I woke up not even knowing what a stoma was and struggled to come to terms with my new way of life. It felt like I had nobody I could turn to who would understand and I felt very isolated.

I became a member of the closed facebook group and this helped me immensely. The group gave me people to chat with and I realized I was no longer on my own. Then I decided to ask if there was anybody out there who would like to help me set up a support group in the Northampton area. Ian contacted me and mentioned wanting to start a group a few years before.

A year on our group is flourishing. We have a great time. As a group we share our stories, our ideas, our tears and our laughter. We have all made new friends and I hope our group continues and develops for many years to come.

We meet every two months on a Wednesday evening from 7pm to 9pm at:

St John the Baptist's Church Chapter House

The Green, Kingsthorpe Village, Northampton NN2 6QD.

Dates for next meetings:

Wednesday 15 November 2017

Wednesday 17 January 2018

For more information contact:

Ian 0780 1316 403 (evenings)

Trish 0770 3188 386

SASH

Freephone
0800 389 3111



Ref. No. HB102

Stoma Support & Hernia Belt Ref. No. HB102

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

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

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

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

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



Ref. No. SR103

"The ring of confidence"

Security & Leakage Belt

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

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



Ref. No. SS104

Stoma Shield Ref. No. SS104

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

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

Sash Medical Ltd.

Woodhouse, Woodside Road, Hockley, Essex SS5 4RU Tel: 0044 (0)1702 206502

Web: www.sashstomabelts.com





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Regular donation

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

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 UK, Enterprise House, 95 London Street, Reading, Berks RG1 4QA**. Telephone: **0118 939 1537** if you have any queries.

Note: Please ensure that we have your correct contact details: full name, address and postal code telephone number thank you	My Details: Title:	Name:	Surname:
	Address:		
			Postcode:
	Telephone (home):	Mobile:	
	Email:		

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

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

To the Manager: (Bank or Building Society)

Bank Address: _____ Postcode: _____

Name(s) of Account holder(s): _____

Account number: _____ Sort code: _____

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

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

thereafter until further notice. (Please cancel any previous standing order in favour of this beneficiary).

***Please leave one month's notice to ensure donation processes through banking system and**

state your donation amount in words: _____

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

Account name: **Colostomy UK** Account No: **88781909** Sort code: **60-17-21**

Name: (IN CAPITALS) _____

Signature: _____ Date: ____ / ____ / 2017

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

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

Reason for your stoma: _____ (Please tick) Ileostomy ☐

Year of operation: _____ Urostomy ☐

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

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





Thank you for your support

Single donation

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

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

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

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

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

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

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

Single donation: I wish to make a **single donation** to the **Colostomy UK** 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 UK**

I enclose my **cheque/postal order form** made **payable** to **Colostomy UK** 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 UK – 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

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



National Support Organisations

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

IA The Ileostomy and Internal Pouch Support Group

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

UA Urostomy Association

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

Mitrofanoff Support

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

IOA International Ostomy Association

www.ostomyinternational.org

Junior Ostomy Support Helpline (JOSH)

via the **Colostomy UK** 24-hour free helpline 0800 328 4257
e-mail info@ColostomyUK.org

Breakaway Foundation

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

Support Organisations for associated medical conditions

Beating Bowel Cancer UK

www.beatingbowelcancer.org
Telephone 020 8973 0000

Bowel Cancer UK

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

Macmillan Cancer Support

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

Crohn's and Colitis UK

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

The IBS Network

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

Stoma Care Open Days

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

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

Open Days that we are 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 UK** website.

Stoma Care Open Day

Hillsborough Arena, Middlewood Road
Sheffield S6 4HA
10 October 2017 11am–3pm
Pam Lyons Stoma Care Dept.
0114 271 4015

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

Memorial Hall, Smithfield Street,
Oswestry, SY11 2EG
12 October 2017 10.30am–3pm
Irene Constable 01691 238357
ireneconstable@phonecoop.coop

Derby Teaching Hospitals Stoma Care Open Day

'The Spot', Wilmot Street West
Derby DE1 2JW
12 October 2017 10.00–2.00 pm
Karen Kirkham/Seema Sharma
01332 787465

Channel Islands Stoma Exhibition

Savoy Hotel
St Helier
Jersey
12 Oct 2017 1pm–5pm
Fiona Le Ber Clinical Nurse Specialist
f.leber@fnhc.org.je 01534 445076

Information about forthcoming Open Days in your area may be sent to you by **Colostomy UK**. These invitations are sent by our volunteers, who 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 UK** funds. Your personal details are never disclosed.

SUPPORT

Blackpool Teaching Hospitals Open Day

Health Professional Education Centre
Whinney Heys Road
Blackpool FY3 8NR
21 Oct 2017 10am–2pm
Stoma Care Team

The Outlook Group Open Day

(North Staffs Ostomy Support Group)
Bradwell Lodge Community Centre
Bradwell Lane, Porthill
Newcastle, Staffs ST5 8PS
28 October 2017 1pm–3.30 pm
Moira Hammond 07788 402195
or 07788 107937

James Paget Hospital Stoma Open Day

Wherry Hotel
Oulton Broad
Suffolk NR32 3LN
31 October 1pm–5pm
Stoma Care Team

SE Trust Colorectal Health & Wellbeing Event

Ulster Hospital
Q11C Centre, Trust HQ
Ulster
10 Nov 2017 2pm–4pm
Martina Finn
martina.finn@SEtrust@hscni.net

Stevenage Ostomistics Open Day

The Oval Community Centre
Vardon Road
Stevenage SG1 5RD
25 November 2017 10.30am–1.30pm
Judy Colston 01438 354018
neilcolston@btinternet.com

Leicester NHS Securicare Open Day

College Court
Knighton
5 Dec 2017 10am–12noon
Felicity Nutting SCN
Felicity.nutting@securicaremedcal.co.uk
0116 258 4455

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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

Bristol

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

Buckinghamshire

Milton Keynes Stoma Association
Thia Cooper 01908 679 295 /
mksa.sec@gmail.com
You Are Not Alone Stoma Support
Group
Carla 0784 6354 918

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
East Cheshire Stoma Support Group
Catherine McIntosh: 01477 535 071
Stockport Support Group
Angela Simpson: 0161 320 9400 /
0800 652 6667
Warrington Ostomy Support Group
Jane Shaw: 0192 566 2103

Cleveland

Oops Group
Julie Morrisroe/Carol Younger:
0128 728 4113

Co. Durham

Bishop Auckland Stoma Care Group
Betty: 0138 881 4535 or email:
pgill82171@aol.com
Darlington Support Group
Sister Jacqui Atkinson: 01325 743005
Durham Stoma Support Group
Katie: 0191 3332184

Cornwall

Cornwall & Plymouth Bowel Cancer
Support Group
The Chairperson: 01726 828 419
or The Secretary: 01872 241 145,
cbcsinfo@gmail.com
Cornwall Ostomy Support
Ken Jones: 01872 863 106 or
www.cornwallostomysupport.org.uk
Lanhydrock Ostomist Support Group
Mandy Rowe: 01726 832 642
E: murphy.rowe781@btopenworld.com;
Henry Kendall: 01208 850 986
E: h.kendall380@btinternet.com or Anna
Rennie: E:anna@thesilverocean.com

Cumbria

Grange Cancer Support Drop in
Marie: 0153 953 3279
Stoma Support Groups in North Cumbria
Stoma Care Nurses 01228 814 179

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
Plymouth & District Bowel Cancer
Support Group
Wendy Wilson or Keith Anderson:
07934 922 156 Facebook: Plymouth
Bowel Cancer

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
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 (S.O.S.)
Sally – 07527 707069
Southern Ostomy Group
Caroline or Karen on: 07756 819 291
southernostomygroup@hotmail.com
Waterside Stoma Support Group
Hazel Derham: 0238 089 1934 or
hayjuder@sky.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 Peet: 01772 683 790,
www.phoenixgroupbvh.com or
eMail: sandrapeet7@aol.com

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
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

Northamptonshire

Northampton Ostomy Support Group
Ian: 0780 1316 403 (evenings) or
Trish 0770 3188 386

Northumberland

Berwick Ostomy Support Group
Bobbie Minshall: 0771 447 9320
Hexham Ostomy Group
Judith on 0796 792 7286
Northumberland Cancer Support
members@northumberlandcancer
supportgroup.co.uk

Nottinghamshire

North Notts Stoma Support Group
Tore and Nicky Norman:
0177 371 5460
Nottingham QMC Stoma Support Group
Rosemary Brierley: 0115 982 6691
Nottingham Stoma Support
Jenny or Kate: 0115 962 7736/
Mrs B Heath: 0115 966 3073

Shropshire

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

Staffordshire

Outlook
Moiria Hammond 0778 840 2195

Suffolk

East Suffolk Ostomy Group
Marion Fisher: 0147 331 1204
James Pagett Ostomy Support Group (Afternoon Meeting)
Vicki Blackwell on 01493 663363
James Pagett Ostomy Support Group (Evening Meeting)
Sandra Hutchings: 0150 258 5955
L.O.G.S (Lowestoft Ostomy Group Support)
Mandy O'Shea: 07899 913 617 or
Bruce Pollard: brucepollard@me.com
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. Website: [http://www.
normandystomagroup.wordpress.com/](http://www.normandystomagroup.wordpress.com/)
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 or
 Bob: 07564 680 803

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
 Hambleton and Richmondshire Ostomy Support Group
 Stoma Care Nurses – Judith Smith and Mary Hugel
 Harrogate Stoma Support group
 Jacque: 07768 024356
 Leeds Bowel Cancer Support Group
 Lynda Castle (Colorectal Nurse Specialist) 0113 206 5535
 Scarborough Stoma Support Group
 Stoma Care Team: 01723 342 388
 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

Republic of Ireland

Co. Mayo

Mayo Stoma Support
 Marion Martyn: 094 902 1733

Dublin

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

Scotland

Ayrshire

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

Fife

Fife Ostomy Support Group
 Ishbel Barr: 0159 277 2200

Lanarkshire

G66 Support Group
 Les Ireland 0141 776 3866
 Glasgow Stoma Support group
 Chairperson: Morag Sinclair
 0141 779 1322 or Jackie McChesney
 01505 324 052

Moray

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

Scottish Borders

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

West Lothian

GOSH (West Lothian)
 Scott Pattison: 07502 163 644

Wales

Bridgend

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

Carmarthenshire

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

Conwy

North Wales Ostomy Support Group
 Hazel: 07976 817 246 or Lesley:
 07828 837 325

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

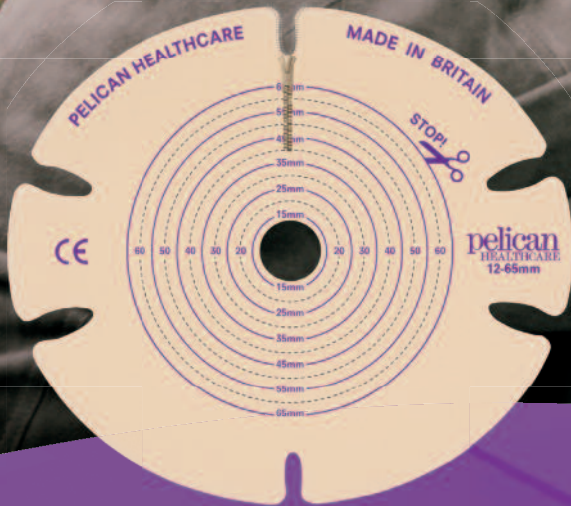
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If you would like your samples pre-cut please indicate the size you require:
_____ mm

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