

Tidings

colostomy association

Dedicated to Colostomates their Families and their Carers



Cover story

- Trevor living life to the full

Inside

- Other readers share their experiences
- Fistulae explained
- Choosing the right pouch
- And all our regular features

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dear READERS



Welcome to the summer issue of Tidings

The editorial this time is from me, Sue Hatton. After 10 years of developing our flagship magazine, *Tidings*, Jane Wood the Editor and PR & Communications Manager has decided to step down from this vital role with the CA and return to working alongside her husband. On behalf of all the Trustees, Staff, Healthcare Professionals and Readership, we thank Jane most sincerely for her dedication, passion and hard work ensuring this nationally acclaimed publication has been so successful. We wish Jane all the very best for the future.

We're pleased to advise that Arvind Anand, our Marketing & Fundraising Officer, has taken on the production of, *Tidings* and he is working closely with our Editorial Team, advertisers, writers and contributors. Arvind has experience in working for two charities, as well as in print and publishing.

Having also worked for a government supplier of IT communications equipment, Arvind also provided consultancy services to provincial newspapers and worked for a national automotive magazine publisher.

The next edition of *Tidings* will be available in early October and Arvind will continue to produce the magazine to its usual high standard every quarter, while aiming to make it even more beneficial to ostomates and their family members.

For the last five years it has given me such pleasure to hear from you about your irrigating experiences and receive your hints, tips and suggestions to include on the irrigation pages. However, as many of you know, I now have an ileostomy, not a colostomy, which means I can no longer irrigate. So I have handed over compiling the irrigation section to Sarah Squire. I felt that it would be more appropriate that she should respond to your letters and e-mails.

However, I will always continue to champion this method of bowel management wherever I can.

Sarah, with her experience in medical research, has also been liaising with healthcare professionals and sourcing articles on medical topics related to stomas. This time we have an article on fistulae (I felt it was important to cover this topic in *Tidings* as I know from personal experience what a problem these can be). Also, as an administrator on Facebook, Sarah continues to be responsible for the *Tidings* Facebook page and in this issue she reports on the very successful Meet-up in Lancaster in May.

I am particularly delighted that we are including an update on *Ostomy Lifestyle*. We hope you enjoy seeing how the great work achieved by *Ostomy Lifestyle* is continuing to be supported by the CA. Our general manager, Sue Hale, also keeps us up to date with what's happening at head office. On the fundraising page she highlights the different ways you, our supporters, have raised funds for CA. Thank you all for your fantastic support.

Rosemary Brierley, former *Tidings* editor and long-standing member of the editorial team, has taken on the task of looking through the articles, letters and e-mails you have sent us. At our editorial meeting for this issue we selected a story written by Alison and another by Trevor, both of whom have experienced ill health and loss in their lives, but moved on and achieved so much. We also chose Ken's account of how it feels when your partner has two stomas.

Thank you for all your letters and e-mails. Rosemary has done her best to include them all on the Readers' Writes page and passed on your stoma related queries for our nurse, Julie Rust, to answer. Please do keep those responses, comments and queries coming into office and continue to use the editor@colostomyassociation.org.uk and we will be happy to hear from you.



**Sue Hatton
Executive Trustee**

Email:
editor@colostomyassociation.org.uk

How to get in touch with the Colostomy Association

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

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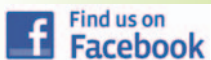
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inside

all your regu

regulars

3 Welcome
From Sue Hatton

9 From our President
Ian Daniels writes: A day in the life of Dr Bottom

40 Fundraising
A thank you for your generous donations and fundraisers

54 Notebook
Helpful organisations

56 Connections
Advertise your events here • classifieds

57 Donation Forms
For regular and one off donations

update

9 10th Anniversary Celebrations
What's in store for this big event?

8 CA Awareness Day
4th October 2014

18 New Products
Keep up to date with the latest products and services

27 Ostomy Lifestyle
What's happening at Ostomy Aid?

from healthcare professionals

43 Specialist Nurse Education
Pat Black asks: "is it important?"

44 Fistulae
Jennie Burch explains

45 Modern Technology
Jo Sica tells us how she communicates with her patients

46 Dear Nurse
Julie Rust answers your letters and e-mails

this issue

articles & special features

from our readers

7 **Nothing stops me now**

Alison Butterworth

10 **A Partner's Perspective**

Ken Minshull

25 **From One Ostomate to Another**

Readers' experiences, hints and tips

29 **Living each Day to the Full**

Trevor Andrews

49 **Readers' Writes**

Your letters and e-mails

travel



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practical issues

15 **Choosing the Right Pouch**

A basic guide for the new ostomate

22 **Irrigation**

Noreen describes her experience

Support

34 **The Breakaway Foundation**

Support & Guidance at a time when it is needed most

35 **Medikidz**

Explaining stomas to children

37 **Facebook**

Sarah Squire reports on the latest Meet-up

59 **Diversions**

Support for families of children living with a bladder or bowel problem in the North West of England

60 **List of local support groups**


cover story



Living each Day to the Full Trevor Andrews

featured on page 29

96%

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Discretion.

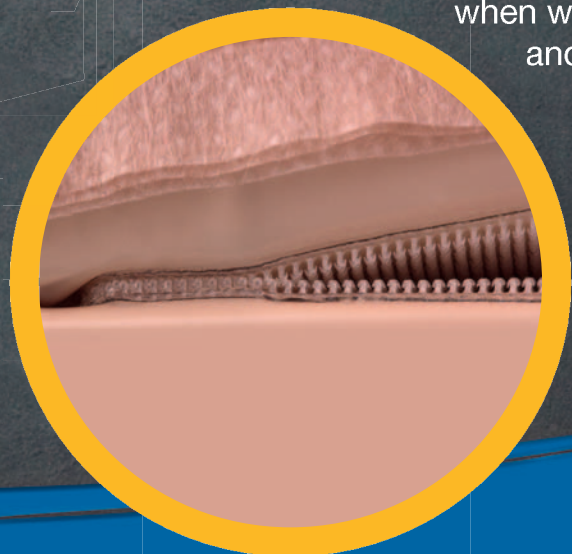
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Nothing stops me now!

“...but the one thing that has been constant is my stoma: it saved my life!”



The youngest of three children, I had a lovely childhood, we were a really close family. However, in 1976 my lovely mum was taken ill and had surgery.

They discovered an 8lb cyst in her womb which was removed but the ovaries were left as she was only 43. I was 11. In the years that followed she went on to develop ovarian cancer and passed away in 1981 aged 47. I was 16. Our family was devastated and in shock but then when my grandmother developed breast cancer and passed away three years later it was all too much.

But life goes on. I married and had two lovely boys. However, my marriage failed and I spent ten years on my own with my boys. I worked hard and we had a good life.

In 2001, I met Neil. He was 29 and we just hit it off straight away. Neil had never had any children so we decided to try for a child and, although I was 38, Lauren Daisy was born in 2003. Neil and I married in June 2004. I was 40 in the September so we booked a trip to London for the weekend to celebrate and had a fabulous time.

While in the shower I found a small lump on the left side of my pelvis. My thoughts went straight back to my mum and as soon as we returned home I went to see my GP. I wasn't surprised when I was referred to the hospital.

I saw my gynaecologist and he confirmed it was something to do with the ovary. I was gutted, but carried on until December 2004 when the lump was the size of a grapefruit.

I had lost a lot of weight and was now down from 11st to 8st 4lb.

By Christmas I could neither sit, stand or sleep so I took myself to KeyDoc (our out of hours GP service) on 24th, 25th, 26th and 27th of December and each time they sent me home, as my surgery date was 20th January 2005.

I took myself back on 29th December and pleaded with them to take me in earlier as I hadn't been to the toilet for ten days. They operated on 30th December 2004.

I awoke from the surgery and instantly felt better. It was a New Year. I remember asking for orange matchmakers! I was on a drip and had a catheter. A nurse told me I had a colostomy. It had never been mentioned prior to surgery. I didn't know what a colostomy was or how long I would have it. I had to wait four days to speak to my consultant, who, when he turned up, bounded into my room with thumbs up shouting: "We got it all." The surgeons had, in my best interest, decided a colostomy was necessary.

It was six days before I told my sister as all I felt was pure revulsion. My sister explained everything to my husband who then told my boys; their reaction was totally unexpected but wonderful: "My PE Teacher has one of those and nothing stops him, it's no big deal", Neil laughed. Children are so accepting. I recovered, had chemo and radiotherapy and life carried on.

In 2007 I was diagnosed with breast cancer. Chemo and radiotherapy followed and I

chose to have both breasts removed in 2009 as I have the faulty gene, BRAC2. I have coped with so much but the one thing that has been constant is my stoma: it saved my life!

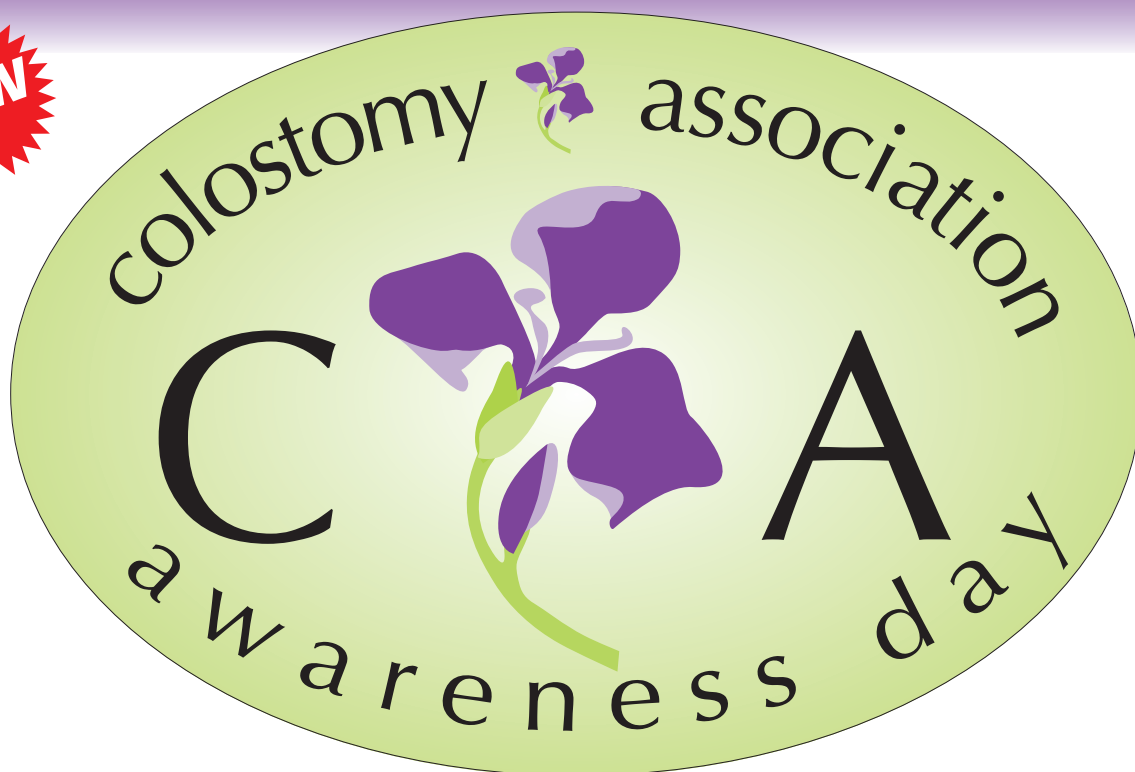
In 2013 I decided to train for the *Race for Life 5K*. I joined the gym and ran it in 41.21 minutes, raising £600 for Macmillan. The girls at the gym put me forward for the *Corby Sports Get Active Award* and I won it! I'm back in training as this year Lauren is joining me for the 10K race.

My family are my inspiration; the comments from my boys really helped – just knowing that there was someone else living their life 'well' with a colostomy definitely helped me. **Nothing stops me now!**

I will be 50 in September – I never expected to live beyond 40, yet here we are together as a family ten years on! Another trip to London, a show and some orange matchmakers is on the cards!

Alison Butterworth





CA Awareness Day – 4 October 2014

Every three years World Ostomy Day promotes international awareness of those living with a stoma

Think Local

This year we're launching our very own CA Awareness Day to complement this internationally-recognised Ostomy Day and we'd like your help! Could you organise an activity in your area? It wouldn't have to be large or elaborate – even a simple, small scale event would be great!

Our vision is to have as many CA supporters as possible running an activity on the first Saturday in October. Can you help us launch this special day this year? Imagine, a whole series of activities across the UK – all promoting our charity – on that one special day.

Please help us!

By raising our profile in your local community, not only will we be able to reach out to those fellow ostomates who are not aware of the CA, but you'll also raise vital funds to enable us to continue to provide much needed 24 hour support.

Need Ideas?

To whet your appetite – how about one of these suggestions? The activity could be a table top sale, quiz night, cake sale, coffee morning in your own home, sponsored silence, open garden, golf tournament, swim-a-thon through the local school or a mile of one penny pieces through your Scouts/Brownies club. The list of possibilities is endless!

Free Pack

To help you get started, we're offering a CA Awareness Day pack which will contain a sponsorship form, a poster, a donation box and a sheet of activity ideas, as well as a set of quiz questions and a surprise item to act as a personal collection bag!

Interested?

Please book the date in your diary, get your thinking caps on and see what you can do on **Saturday 4 October** this year. Thanks so much!

To obtain your **free** pack, please contact the office ideally by emailing CASS@colostomyassociation.org.uk or by telephoning **0118 939 1537**. We hope to hear from you soon!

A Week in the Life of Dr Bottom

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

Monday: Bank holiday, so a day in the garden...No time to write a lecture, or two. Garden beckoned, lecture not written...Doh! Why do I do everything lastminute.com?

Tuesday: Busy day, flight to the north, via Manchester. I never knew I needed my passport to get into Manchester...and out again!

Wednesday: Conference in Edinburgh: still part of the UK, currency still similar, electricity on, lots of Europeans here... realised they're not tourists, but delegates at the conference...still not written lecture! American surgeons insist on taking pictures...must have thought the President was in the building...realised I am!

Thursday: Nice dinner at The Royal College. Lecture today, better write it, am

giving the State of the Art Lecture on Parastomal Hernias...Hmm, lots of evidence to review...or not as the case may be. Added a few pics, reviewed the evidence. Lecture well attended, must be the Presidential thing. Told them no matter what we do surgically, a patient's best friend is their stoma nurse...if they still see one. Anyway, another dinner, suddenly getting attention, turns out no one knows much about parastomal hernias, suddenly everyone interested. Now where do I get a deep fried Mars Bar?

Friday: On good form today, lecture done, now chairing sessions and listening to other lectures. All very interesting, still no one says anything about stomas, think to myself there is much to be done here. Colleague from Exeter, the Smart One, gives lots more talks, sit back and remember, "When he



was my registrar!" Friday night enlivened by a dinner at the Scottish Museum, met a fellow clan member wearing the same tartan. Decided we must be brothers... well underneath the kilt anyway.

Saturday: Arrive home, grass grown again, back to being a gardener! Still thinking about hernias, might ask my friends at the CA for some help...

*Ian Daniels with Chris Oppong,
Consultant Colorectal Surgeon, Plymouth*

2015 - Special 10th Anniversary Celebrations

Next year we'll be celebrating our **10th Anniversary** and we hope you'll join in the fun! This special milestone provides the ideal opportunity for us to raise our profile further across the UK and your involvement would be highly valued.

Our patient open day will take place in Reading on **Saturday 11 July 2015** followed by a celebratory dinner/dance that evening. On the Sunday morning we're planning to hold a fashion show full of glitz and glamour so do put the dates in your diary if you'd like to come along! Sponsorship is being sought to help cover the cost of these special events but any fundraising our supporters can do to assist will be much appreciated. However, the dinner/dance will be a fee paying event.



Tickets for these special events will be available early next year once all the details have been finalised so look out for more information on our 10th anniversary plans in a future editions of *Tidings* magazine.

We also hope you'll get involved by running your own local celebratory activities -

perhaps on **CA Awareness Day (on Saturday 3 October 2015)** - to make it an extra special year for us. Your involvement with these celebrations would be greatly appreciated. Thank you!

The CA has come a long way since 2005 and we're going from strength to strength thanks to the generosity of our supporters and the commitment of our invaluable volunteers.

We simply could not provide our 24 hour helpline service without your kindness and efforts. Thank you all so much for your ongoing support and dedication. We look forward to serving you for the next decade and beyond!

A Partner's Perspective



Regular readers may remember reading Bobbie Minshull's story in Tidings Issue 30. Bobbie is a CA volunteer who has both a urostomy and a colostomy. We asked her husband, Ken, to tell us their story from his point of view.

My personal experience started early 1984 at RAF Bruggen in Germany, when my 27 year old wife, Bobbie, suffered an ectopic pregnancy, followed by cervical cancer the following year. In both cases, the Air Force way of dealing with the problem was to CASEVAC (casualty evacuate) her back to the UK, unescorted, for emergency life threatening surgery, leaving me abroad with two young girls of two and seven to look after. The alternative was for them to be

taken into care many miles from their mother and father! It was only the efforts and support of a small number of very special people, to whom we are eternally indebted, that we coped.

Bobbie subsequently needed radiation treatment in the UK (co-ordinated by my parents, who were the unbreakable rocks we leant on). Unbeknown to us, this unfortunately led to severe damage to her bladder and, we were to find later, also to her bowels.

All this pre-stoma...

On return to the UK, things seemed fine, notably through tours at Kinloss and then a wonderful Norfolk base at Swanton Morley.

However, even then the signs were showing, with bladder control becoming more of an issue. Subsequent operations included an attempted bladder lift where the wall actually split! I can honestly say that it tears at your heart when your soul mate loses all sense of control; we knew every available toilet on any walk we went on. Finally, the inevitable happened and she was given her first stoma (yes folks, there's more to come...) at Norwich in 1991.

What did I know about stomas? Nothing! What did Bobbie know? Nothing! No stoma nurse available so it was basically a 'get on with it', with most information coming from the Urostomy Association and stoma delivery companies. Fortunately, Bobbie is

very positive and resilient (she has to be looking after me...), and rode the changes well. With the help of others who knew about subsequent needs (try going to a Sergeants Mess ball and escaping during the meal...), we began to enjoy life again.

As the years progressed, Bobbie began to get more spasms in her abdomen. This meant more surgery and less bowel control. From early 2002, we were living in Maastricht, where they had an excellent university hospital. The artificial sphincter would have worked if Bobbie's bowel was not so short and her output so loose. This was subsequently determined during a revision of her urostomy, when a second surgeon was called in just to sort out the bowel damage and adhesions. Six hours of surgery to tell us something that should have been documented and discussed years ago!

Well, from there the inevitable happened and Bobbie elected for a colostomy as the only way to control things and get life back to normal. It seems strange that all those years back in the UK and no one was there to discuss future options, so, when it came that a colostomy was necessary, we still had to find out the information ourselves.

As for me, while I had nothing but admiration for how Bobbie coped with the issues, this was the straw that broke the camel's back. I don't know why as a colostomy did not revolt or scare me. I had just had a call from my younger pharmacist

brother who just said, "Don't worry Ken. I know you will both do the right thing". Well, I broke down in my office (and I'm still welling up remembering today). One day, one comment, that's all it took and after all those years I couldn't cope! Then, as fate often does, it lent a hand. In walked our cleaner Inge, a Belgian lady, larger than life in character with the most outrageous sense of humour (I will leave her use of the vacuum cleaner up to your imagination). Apart from the initial "sorry", she stayed and talked. Apparently her father had two stomas, so she had a good insight to life with them. She was fabulous, to this day my special guardian angel. She even wanted to know if she could come and clean my house or do the washing to help!

Well, the operation went well and Bobbie is living comfortably with her twin stomas, Fred and Steve (another story). I have no problems with living with her stoma and supporting her throughout; I even helped remove the stitches from 'Steve' and would do anything to support her.

In the mid '80s the goal was to survive, then see the children grow and now the grandchildren. We have maintained a full and active life throughout and still ski and play golf regularly (experienced an issue on where to place the stoma there), walk, swim, take holidays and take a good bashing from the grandchildren. We also wake up to a cuddle every morning now I have retired; my wife is my life and life is good!

Conclusion: The big wake-up call is that partners are often forgotten. Regardless of how long something has been around, how simple or complicated a situation, knowledge is power and that power breeds strength. We are here as the rock for our loved ones to stand on. There is no point in us complaining as it is they who have to put up with the pain, the recovery, the immobilisation, the change to their routine and the always evolving use of stoma products (another experience issue), not us.

However, on the other hand, while worrying about surgery and the change to their lives, our partners are also concerned about the effect on 'our' lives as well, which just adds to overall stress levels. They love us no less because of changes to themselves; just worry more how those changes reflect on us. The earlier lifestyle changes can be discussed openly the better. Not all partners will want to know, but from my experience I would have certainly benefitted from open dialogue, not just the once but throughout the years. The more partners who can 'be there' for new ostomate partners can only be for the good. I for one will always be available.

Finally: If you can help someone using your experience, it just proves, nothing is so bad that good can't come of it.

Ken Minshull





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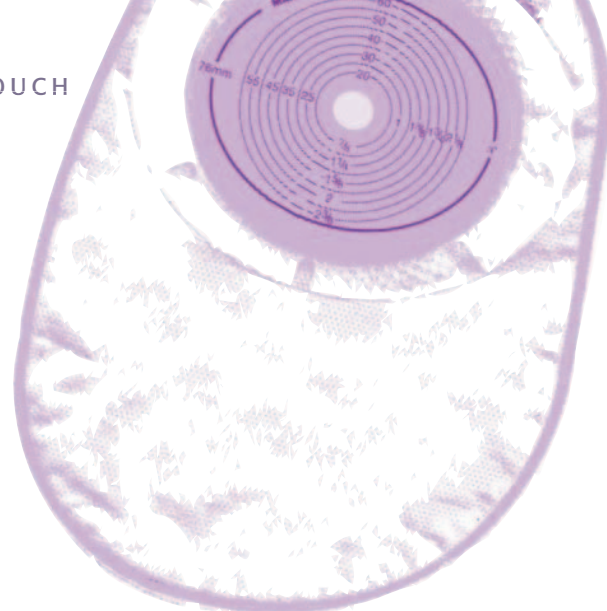


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Choosing the Right Pouch



More than a dozen different companies manufacture stoma appliances, and each one has a wide range of products.

Pouches can be one-piece or two-piece and both of these can be either drainable or closed. They all come in different shapes and sizes and there are also those with special features to cope with specific stoma problems.

Drainable or Closed

After surgery it may be a while before the stoma starts working. When it does it will first of all produce wind and then a fairly liquid output. So on returning from theatre a new ostomate will usually be wearing a post-operative drainable pouch. This will make it easier to release wind and to empty fluid motions. The pouch may be made of transparent plastic so the nursing staff can check on the stoma. They will want to observe when the stoma begins to work and make sure the join between the skin and the bowel is healing well.

Before you leave hospital the stoma care nurse will select the pouch which is most suitable for you at the time. If you have an ileostomy the output from your stoma will always be fairly liquid and you will be advised to continue with a drainable pouch. If most of your colon was removed when your colostomy was formed the output may also be liquid. Again a drainable pouch may be best. There are many, many different types to choose from so it is not likely to be the same as you were wearing when you came back from theatre.

If you still have most of your colon intact then after a period of rehabilitation your motions will probably be formed rather than liquid. So your nurse will suggest a closed pouch. Again there are very many to choose from. When a closed pouch is about half to two-thirds full it needs to be

changed for a fresh one. Some people also like to make sure their pouch is empty before they go out and before they go to bed. This means that it may be changed several times a day.

If you have concerns about disposing of these used pouches your stoma care nurse may suggest a toilet-flushable version. This has an outer pouch and an inner liner. When it needs changing the outer pouch, which is unsoiled, is removed and can go in the bin. The inner liner contains the motion and is flushed down the toilet. At present only one manufacturer produces this type of pouch.

One or Two Piece

Both drainable and closed pouches can be one-piece or two-piece. In a one-piece pouch the flange (the pad of adhesive which sticks onto the skin) comes already attached to the pouch. In a two-piece system the base-plate or flange is separate and can remain in place around the stoma for two to four days. Used pouches can be removed and replaced as required. The advantage of this is that the skin remains undisturbed whereas frequent removal of a one-piece system can lead to sore skin.

A two-piece system can also be useful if you find it difficult to position the appliance around the stoma. If necessary, a relative or carer can help to fit the base-plate every few days and then in between you can change the pouch without assistance.

The pouch either clips or sticks onto the base-plate. Although the clip-on system can be more bulky and rigid, you may prefer it, particularly if you have impaired vision, as you can hear the sound as it snaps into place and then check with your fingers that the seal is secure. The stick-on system is slimmer, more like a one-piece, and is easier to manage if you have restricted hand movement due to arthritis.

Flange, Base-plate or Adhesive Wafer

Whatever you call it, the adhesive part of your appliance needs to form a secure seal around the stoma and not allow any of the output to seep beneath it onto the skin. To accommodate all sizes and shapes of stomas and any problems that can arise, different types of flange, base-plate or adhesive wafer are available:

If your stoma is an irregular shape, or if you have trouble cutting a hole to fit around it, a mouldable base-plate may be the answer.

If your stoma is flush with the surface of the skin, or retracted below it, a soft convex flange may be best. The soft, raised circle around the hole gently pushes the stoma forward so that the motion drops into the pouch. This can also work if there is a moat (a circular indentation) around the stoma.

If you have a parastomal hernia a flange or base-plate with a flexible outside edge may help. Slits or flexibility around the circumference mean that it will fit around a curved surface without any creases or wrinkles which can be a channel for leakage.

Hydrocolloid has been used for many years to make the familiar yellow base-plates and flanges. All the manufacturers have their own secret recipe and ostomates generally find that one manufacturer's product suits them better than another.

As an alternative to a hydrocolloid flange there is Microskin, a transparent wafer as thin and flexible as *Clingfilm*. It follows the contours of the skin so if you have creases or crevices around the stoma it can help to prevent leaks.

Mix and Match

Different pouches for different occasions

Pouches come in all shapes and sizes from mini to maxi. Minis have a small capacity for times when you know your stoma is unlikely to be active or for going swimming, while maxis can be worn for longer periods of time or by those who have a high output during the night. There are also stoma caps which are suitable for intimate moments or for those colostomates who irrigate.

The same pouch usually comes in both closed and drainable versions. If you normally use a closed pouch it is a good idea to have a few drainables as they will be useful if you have a stomach upset which results in loose motions. Remember to take a small supply on holiday – just in case. Also on your journey it might be an idea to use a drainable as it can be easier to empty, rather than change and dispose of a pouch.

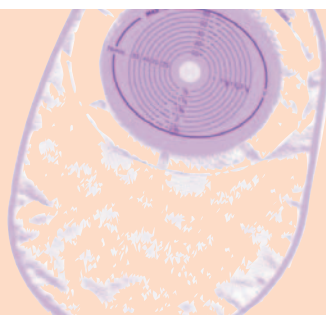
If you use a two-piece system, it is still possible to ring the changes – closed, drainable, smaller pouches and stoma caps are all available to fit the same base plate.

Finding the Right One for You

Many of the products mentioned above are advertised in Tidings. If you feel one might help, ring the manufacturer for samples or contact your SCN. Or you could see a range of stoma appliances first hand by visiting a stoma care open day.

There are those of us who are happy with the pouch we are using and say 'If it's not broke don't fix it'. However, if you are having problems remember there is a very wide range of different pouches available. There is one out there to suit you and your SCN should be able to help find it.

Types of Pouch/Bag



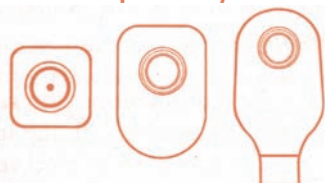
Closed pouch



Drainable pouch



Two-piece system



One-piece system

If you decide to try a different appliance, here are a few points to bear in mind.

- Try a new pouch on a day that you are not going out so any mishaps can be easily rectified.
- Take it slowly. Try a new pouch for a few days. If it's no improvement go back to your usual bag and wait a while before trying another.
- Your stoma care nurse is there to advise you. If possible, it is always best to seek her advice. Before using some types of pouch, for example those with a convex flange, it is important to check with your nurse that they are suitable for you.

Advantages

- More suitable for coping with formed motions.
- Replaced with a new pouch one or more times a day.
- One manufacturer produces a flushable version, which can be disposed of down the toilet.
- More suitable for coping with a liquid output
- Does not require changing as often as a closed pouch.
- Fewer pouches are used.
- Easily emptied, prior to disposal.
- Base-plate (flange) can remain in place for two to four days, which is kinder to the skin.
- The "stick on" system may be easier for ostomates with arthritis.
- The "clip on" system may be easier for visually-impaired ostomates.
- Less bulky and more flexible.
- May adhere more securely to scarred or uneven skin.

Disadvantages

- Less suited to managing a more liquid output.
- The pouch may need to be changed and disposed of while away from home.
- Disposal of several used pouches every day may be a problem.
- May be difficult to empty if the output is of a thicker consistency.
- Careful cleaning of the outlet is required.
- Clip or fastening can be uncomfortable.
- Some people may find it difficult to keep the flange (base-plate) clean.
- Leakage behind the flange may remain undetected and lead to sore skin.
- Some systems are fairly rigid and bulky.
- Every time the pouch is changed it has to be accurately positioned around the stoma.
- Frequent changing of a closed pouch may lead to sore skin.

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* "Effect of a long life ostomy seal on faecal enzyme activity" by Dr Grace McGroggan, TG Eakin Ltd and Dr Lorraine Martin, Queens University, Belfast

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HEALTHCARE

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.

Safe, Dry, Secure...**NEW Astoa®** advanced stoma accessories.

The **NEW Astoa** range of accessories from OstoMART Ltd have been expertly designed to provide increased absorption, flexibility, leakage prevention and skin protection whilst providing you with increased security and confidence.

NEW Astoa Barrier Cream will help to maintain skin integrity, prevent skin irritation and support the natural barrier properties of the skin without affecting the adhesion of the appliance.

NEW Astoa Mouldable Adhesive Ring Seal is available in 3mm THIN and 4mm



STANDARD options and is highly mouldable so you can stretch it, break it, reshape it,

mould it and seal it to fit even the most awkward of areas.

NEW Astoa Hydrocolloid Flange Extenders are available in WIDE, SMALL and LARGE options and is designed to secure the appliance to the body whilst helping to protect the skin from excoriation and maceration. They are extremely flexible with fantastic elasticity benefits so you can bend and stretch and the tape will move with you.

For further information please see our full page advert on the back outer cover or to request free samples please call Freephone **0800 220 300**, email enquiries@ostomart.co.uk or visit our website www.ostomart.co.uk



OakMed would like to introduce their new CURVIES.

Curvies are super thin flange extenders made from a silicone adhesive. This means that they can be used to help extend the wear time of your flange by preventing it from rolling up at the edges.

They have the ability to keep a consistent gentle adhesion throughout their use. They can be repositioned if needed without losing any of their tackiness whilst also being very gentle to the skin.

Curvies are now available on prescription.

Please see our advert on p52 or call us on freephone 0800 592 786 for more information or samples.

Hyperseal®
with Manuka honey



CliniMed's kindest range of stoma accessories yet!

To security, we've added comfort...

Recently launched by CliniMed, HydroFrame® with Manuka honey flange extenders and Hyperseal® with Manuka honey washers are our kindest range of stoma accessories yet.

With the inclusion of Manuka honey, which may help to promote healthy skin around the stoma and made from flexible, skin-friendly Hyperflex® hydrocolloid the combination results in both comfort and security for even the most sensitive and vulnerable skin.

HydroFrame with Manuka honey and Hyperseal with Manuka honey are suitable for use with all types of stoma pouches and are ideal for problematic stomas. With additional adhesion where it is needed

most, they help to prevent leakage and are available in different sizes depending on the need.

For free samples, contact the CliniMed Careline on **0800 036 0100** or visit the CliniMed website www.clinimed.co.uk for further information and advice.



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HEALTHCARE



To security, we've added comfort



Uneven surfaces around a stoma can make life with a stoma pouch difficult. HydroFrame[®] with Manuka honey flange extensions and Hyperseal[®] with Manuka honey washers are designed to provide extra security and prevent leaks, even for problematic stomas. To that security we've added the comfort of medical grade Manuka honey, which may help to promote healthy skin around the stoma. Live life to the full with our kindest stoma accessories yet.

 Careline: 0800 036 0100  www.clinimed.co.uk

 enquiries@clinimed.co.uk

Hyperseal[®]
with Manuka honey

HydroFrame[®]
with Manuka honey

For a **free sample** of HydroFrame, Hyperseal or HydroFrame Mini with Manuka honey, please complete the coupon and return it to: **CliniMed Ltd., FREEPOST HY241, High Wycombe, Bucks, HP10 8BR (NO STAMP REQUIRED)**, call the CliniMed Careline on **0800 036 0100** or visit www.clinimed.co.uk

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

Mr/Mrs/Miss/Ms: _____ Initials: _____ Surname: _____ Address: _____

Postcode: _____

Tel. No: _____ Email: _____

I understand that this request will be handled by CliniMed Limited or SecuriCare (Medical) Limited. I would like my details to be kept on file, so that I can be kept up to date with information about relevant new products and services.

Update on stoma care products and services

CD Medical produces a range of high quality, innovative stomacare products which offer a number of benefits for the end-user whilst also providing significant cost savings for the NHS.

Peel-Easy was the first non-sting adhesive remover available in a bag-in-can spray. Unlike traditional aerosols, there are no cold propellants and it can be sprayed in any direction, even upside-down! Peel-Easy Spray is complemented by Peel-Easy Wipes which gently clean away any stubborn adhesive left on the skin.

Clinifilm's advanced soothing silicone technology delivers a transparent film of protection which is specially designed to shield the skin. Like Peel-Easy, *Clinifilm* is available as a gentle wipe and bag-in-can spray.

The range is completed by *Clinifresh*. A lemon and lime deodorant spray which helps to neutralise any troublesome odours.

For more information or to request a sample visit www.cdmedical.co.uk or call 01942 816184.



Salts WipeAway PLUS – Removes and Refreshes!

Salts are pleased to announce the launch of a fantastic new no-sting 50ml adhesive remover spray called *WipeAway PLUS!*

Not only does this new product effectively and gently remove adhesive, it also has a fresh mint fragrance which helps to mask odour during pouch changes – 94% of users agreed in our trials!

The 'bag-on-valve' technology means that the can sprays easily at all angles - 360°. The spray is also quiet for discreet use, and it won't feel cold on the skin.

To order your free sample today please call **Freephone 0800 626 388** or visit www.salts.co.uk for more information.



Irrigation and you

Sarah Squire, Trustee writes: Sue Hatton has asked me to take on the irrigation page following her transition to an ileostomate. Like Sue I am a passionate irrigator and believe that any colostomate who is interested, and able to irrigate should be supported in giving it a go. I appreciate it isn't for everyone, but for others it offers an alternative way of managing a colostomy which gives some of the control back to the ostomate. Noreen has written about her experience which I hope you will find interesting.

Sarah writes: As you know I encourage everyone who irrigates to write in with their experiences. If you have an irrigation story to share – it would be great to hear from you!

My Colon, My Stoma and Me

Noreen writes: As a very new irrigator I thought my experience might be useful for those hesitating to go down this route.

I had done research into irrigation prior to my cancer operation and knew that this was often an option for those with end colostomies. I was very upset but not entirely surprised when my surgeon said that a colostomy was something he felt he might have to do once he had had a look at my internal workings.

So when I came round from the operation with a permanent colostomy my thoughts turned immediately to irrigation. I knew I had to get over the operation and then chemotherapy but always the objective was for me to be in control. I had missed out on the very best option of reversal, but I was fully aware of the fact that I was much luckier than very many people and I did have a second chance of regaining the control I so desperately needed.

Unlike many, my main problem is not bags of poo but noise. There are times at work when I must have complete stoma silence and I need to be 100% confident that I can have up to six hours without any noise or, at the very most, noise that is no more than a faint unidentifiable gurgle.

As soon as I was fit enough I asked the stoma nurses to teach me to irrigate. Strangely this was not a procedure they were promoting.

I had my first lesson at the hospital and I was very excited. I had done a huge amount of research, watched a video, investigated online all the caps and plugs and, most importantly, I had had a long chat with Judy at the Colostomy Association. She is a huge

fan of irrigation and told me that she has been irrigating for seventeen years. Her help was invaluable. By the time of my first lesson I knew at least as much as the stoma nurses about the whole procedure and had to be very careful to keep myself from bubbling over with enthusiasm and treading on their toes!

The lesson went well with no problems. I went home with a bag and nothing happened. There wasn't much noise to start with although this increased to a sort of occasional gurgling by the end of the day. The following morning and there was still no poo. I was ecstatic! I returned to the hospital for lesson two which also went well.

The following day the stoma nurses came to my home to check me out and then I was let loose. Everyone had told me that we are all different and that I just needed to fathom out through trial and error what was going to be right for **My Colon, My Stoma and Me**. There are so many variables which can affect the outcome. Water temperature and quantity, speed of water input, the way one sits or stands, diet, time of day one irrigates...the list goes on. I am slowly working through all of these variables and trying to assess each individually.

So what has gone right so far? Well, the slight nausea I felt at times when the water was infused disappeared after five or six irrigations. My Colon obviously got the message and accepted that this was the new routine. My Stoma didn't seem to have any problems and went with the flow – quite literally! I have learnt the direction of My Colon and can now fairly accurately aim the cone the correct way. Sometimes I get this a bit wrong and water splashes out of the top of the sleeve but, by and large, I've cracked that one. I have learnt that warmer water is more comfortable and, I think, more effective. What was coming out was much warmer than what was going in so I simply increased the temperature to match.

I am experimenting with the way I introduce the water. I have learnt that there

will often be a small amount of faeces just inside My Stoma, almost like a poo plug. I need to irrigate that out with a small amount of water before the rest can be infused.

I have learnt that I will usually get cramps when My Colon wants to evacuate. I then need to stop for thirty seconds or so and evacuation happens almost immediately. This seems to happen after I have infused about half the water so I pause at that point. Sometimes the water stops going in, presumably when it reaches a large lump of poo, and it then starts again on its own – it's fascinating stuff! I am currently experimenting with leaving 500ml until evacuation seems to be complete so as to have a final flush out.

All the above happens pretty quickly. I am cautious at the moment, waiting a further fifteen minutes after I think all is done but this doesn't seem to be necessary and the whole procedure is completed in under an hour, including setting up and final cleaning.

So all is going well but what has gone wrong? Well, inevitably, I suppose, I have forgotten that I have the sleeve attached and have pulled it out of the loo at just the wrong moment. I have also had a kink in the sleeve outside the loo which filled with faeces, the weight of which then pulled the end of the sleeve out of the toilet. I have had the sleeve pegged up and it has unclipped although fortunately the pegs remained on the folded bottom end of the sleeve. However, these are minor disasters which you just have to laugh about and remember not to repeat. I am pleased to say that nothing has gone wrong with the procedure itself.

My irrigation now lasts 48 hours except for the occasional tiny blob or two of poo which are easily contained by a stoma cap. The noise problem is greatly reduced after irrigating; understandable, I suppose, as there is nothing to ferment and make gas. My irrigation routine is therefore likely to be flexible, depending on what I am doing and may be every 24 or 48 hours or anything in

Colostomy Irrigation and You DVD

between. My colon seems quite amenable and has definitely learnt who's in charge! My Stoma seems happy too.

My life has been enhanced out of all recognition by irrigating and I forgot very quickly about bags and the associated problems.

From now on bags will be reserved for when I have a bout of Delhi Belly – perhaps in Delhi as I can now travel to the other side of the world without having to think about suitable toilets. This is fantastic freedom! I have virtually no noise, certainly nothing for 12 hours after irrigating. Another huge plus point is that I am able to wear my normal clothes again. I am even able to use support underwear to give protection against a potential hernia. This I had found quite impossible to do with poo trying to get into a bag.

To those of you out there with colostomies which can be irrigated I would say please, please give it a go. We are very fortunate. There are many with ostomies which cannot be irrigated. I am sure all those brave people learn to cope in their own ways; we have the luxury of regaining far greater control and freedom.

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. Many people are put off trying irrigation as they can't quite figure out how it works – it all sounds so fiddly and messy.

Colostomy Association have produced the *Colostomy Irrigation and You* DVD to raise awareness of irrigation and to also clearly explain what is involved to those who may be interested in this option of stoma management.

The DVD shows a new irrigator learning the principles with a stoma nurse then our fantastic volunteer Judy takes you through the whole process from start to finish.

Finally a group of irrigators discuss how irrigation has helped them. Irrigation isn't an exact science; we are all different and develop our own technique over time, so the DVD may be useful for those who

already irrigate too as there are a few hints and tips included.

If you are thinking of irrigating, or just interested to see how it works then the DVD will hopefully answer any questions you have. We've had great feedback so far, from irrigators new and old who have found the DVD useful. The following comment from Jean Hall appeared on the CA Facebook group:

"I bought the new DVD that was advertised in Tidings. Even though I have been irrigating for 5/6 months I thought it would help. It certainly does help! It's nice to see some of our friends on here too. I would certainly recommend it to would be irrigators as it takes all the mystery out of irrigating. Well done everyone."

The CA would also like to thank all the stoma nurses and volunteers involved in producing the DVD and hope that you, the colostomate find it helpful and informative.

Colostomy Irrigation and You DVD

Order Form Colostomy Irrigation and You (Patients)

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

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

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



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*Correct at May 2014, England & Wales Drug Tariff. ¹Product assessment. Data on file at Salts Healthcare.

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From One Ostomate to Another

Hints & Tips

I have just discovered *Tidings* and the **Colostomy Association**. What a helpful and informative magazine. I wish I had known about you in 2007 when I was diagnosed with bowel cancer. My life-line in those days, apart from the stoma nurses, was the excellent charity **Beating Bowel Cancer** who were always ready to help on the end of the phone.

After the early grim days of a new life style I gradually became accustomed to living with my stoma, *Bilbo (Baggins)*, and we now have a comfortable relationship. I am the boss. Occasionally *Bilbo* plays up but generally he is very well behaved. I have read your readers' letters and tips with great interest. One tip I shall certainly use is wearing maternity tights... a great idea at 73! I add my own tips in case they can help anyone out there.

1. After several months of using a closed pouch I changed to a drainable pouch which I find comfortable and convenient, especially when out and about, as it is easy to empty and clean in public loos.
2. I always spray baby oil inside the pouch before applying, which helps the poo slide to the bottom of the pouch easily.
3. When I am going on a day out or on holiday, travelling by coach or on an aircraft, I often wear an additional curved flange for security, not that it is needed. I have not had any accidents/leakage for five years (just twice in the early days of first year).
4. I stay clear of broccoli, cabbage and sprouts which *Bilbo* doesn't like as they blow him up! I also avoid chilli, curry, garlic and spicy food as he doesn't like them much either!

I am very comfortable with *Bilbo*. I am busy and active and consider myself one of the lucky ones, having just been discharged by my oncology consultant after five years.

Sheila

Seeing the Funny Side

Unfortunately I had to spend a few days in a Spanish hospital recently with a suspected bowel blockage. (I have Crohn's and an Ileostomy.) Distressingly I required paper underwear (or a nappy as the Spanish nurse insisted on calling it!)

As my Spanish is almost non-existent the language barrier cropped up regularly. With frantic gesturing I managed to obtain a "nappy" and then with even more vigorous sign language, convey to the young male nurse that I was quite capable of putting this new "nappy" on myself. Or could I?

The only "nappy" available was huge. I unfolded this wonder of design the nurse had left me. Well, I reckon you could have camped out on Dartmoor for a week using this thing as a groundsheet!

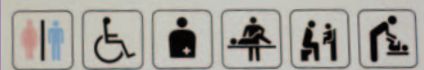
It was the middle of the night and my room-mate had left the night before. I lay looking up at this thing I held up in front of me and weighed up my options. I decided the only way to get this land mass on (it did look a bit like an upside down map of England) was to lay it out flat on the bed.

Holding my nightie up out of the way I launched myself backwards onto the bed in the general direction of the centre probably Birmingham on the map. (That'll teach them for always describing themselves as England's second industrial city when we all know that it is Manchester that takes that accolade!)

With a little shuffling I manoeuvred myself into the middle. The sticky bits at the side were a problem to open and got stuck in all the wrong places as I overlapped the vast surplus of material around my even thinner self. (I hadn't eaten for several days.) So I am afraid I must have looked like a badly wrapped parcel. But Hey, who cares I was in!

Margaret Simister

Japan leads the way



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Ann Carruthers sent us this photo and says:

"Having a colostomy I always have to think about the practicalities of travelling, and last year, whilst visiting Japan, I was delighted to see this notice in Tokyo airport."



"Japanese language and culture can seem alien to a traveller from the west, but we could learn much from the Japanese sensitivity to ostomates."

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

PS: The care I received was actually very good. But don't forget you need both your E111 and passport to receive free treatment in an EEC hospital.

Margaret Simister



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Ostomy Lifestyle update

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

OstomyAid

This project continues to flourish and large quantities of unwanted supplies arrive in Bracknell every day where they are then sorted by a dedicated team of wonderful volunteers. These donations arrive mostly from manufacturers but also arrive due to reversals, allergies, change of stoma size or, sadly, loss of a loved one.

Around 30,000 items are despatched every month to thousands of ostomates abroad who are in desperate need – having to resort to carrier bags or other receptacles to collect their body's waste. One UK based charity, Hospices of Hope, helps OstomyAid distribute supplies to individual ostomates through their hospice in Moldova and this is Luta's story:

*"Hello, I was born in 1949 and I live in Moldova. In July 2010 I had a urostomy due to chronic urine retention and adenoma of the prostate. I started to receive help from Hospice Angelus in February 2011 and to this day I continue to receive urine pouches from the Hospice. I feel very comfortable and thankful. The urine bags I receive from **OstomyAid** are good quality – I feel very safe and very happy with them. Before coming to the Hospice I bought the bags from a pharmacy in a nearby town, but those pouches were expensive and not good quality. I had to use tape to try to make them stick to my tummy. Many times when on public transportation they would crack and smell and I felt very embarrassed. I felt hopeless and unhappy and very rarely could leave the house. Thank you for your help Ostomy Lifestyle. God bless you!"*

Help Needed!

Are you able to help continue this vital work for those less fortunate than ourselves? More volunteers are urgently needed on the ground to assist with the unpacking, sorting, lifting and shifting so do get in touch if you live fairly local to the premises in Bracknell and have some spare time on your hands. Even just a few hours each week will help immensely!

To donate unused surplus stoma products, make a financial donation to enable **OstomyAid** to continue or to find out more about volunteering, please contact: ostomyaid@ostomylifestyle.org or telephone: **0118 324 0069**.



Workshops

The Lottery Funded workshops for support group organisers and those wishing to set up a local stoma support group across England are continuing through Helen Bracey (pictured right). The session looks at the essential elements involved in running an effective support group for people with stomas and includes:

- learning about the different types of stoma and how they are formed;
- learning how to promote a support group effectively;

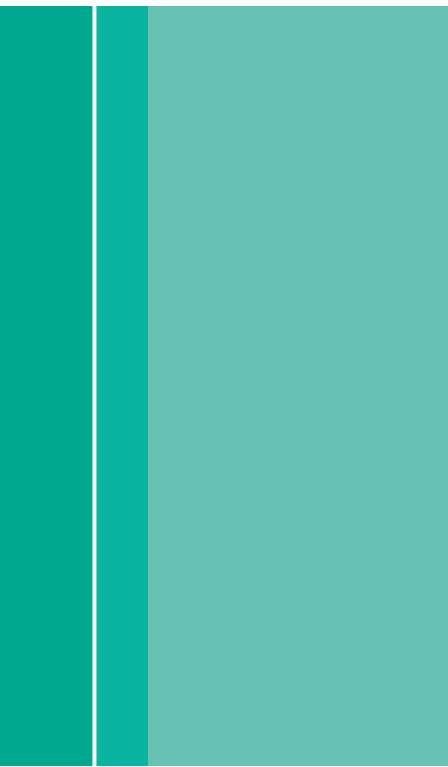
- discovering the ingredients of a good group meeting;
- learning how to handle issues such as conflict and bereavement within the group;
- establishing financial security;
- learning how to ensure there is adequate support at organiser level;
- developing practical skills to help manage the administration of a group, including data protection considerations.



Lunch, refreshments and course materials are provided and up to £50 towards travel expenses can be reimbursed. For those who are unable to make the workshops in person, Helen offers remote delivery of this course via Skype group conference calls. If you are interested in attending or arranging a course in your area, please contact Helen by calling her on **07868 616 374** or emailing training@ostomylifestyle.org

Meanwhile, Colostomy Association continues to provide their administrative support and telephone calls remain diverted to the CA's 24 hour helpline. Further updates will follow about their exciting plans!

For more information, please visit their website at: www.ostomylifestyle.org



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Living each Day to the Full



Trevor writes: This year is the 100th Anniversary of the start of World War I. It was to cause the death of millions of young men at the prime of their lives. So when Lt. Colonel Vassalo told me I had cancer my first question was, "Will I be here in a year's time?" His response was simple: "I am off to Iraq, so I am not sure I will be here in a year's time."

This was 90 years after WW I, it was 2004 and I was at the ripe old age of 57, a lot older than the young men of 1914 but it was still a shock.

I was not in the Army, I just happened to be in an NHS Military Hospital known as Haslar in Hampshire and Lt. Colonel David Vassalo was the Consultant that discovered my problem.

Then came the reality, to survive I needed a colostomy and so my mind started to whizz around again. What about my sailing, have I done my last voyage? Thankfully the answer was no, he assured me.

The next thought was more difficult. I am a naturist – I do not like wearing wet swimming costumes or getting suntan lines! Can I still go sunbathing and swimming naked? Well I did not ask him that one but it was on my mind.

I was happily married with two beautiful daughters so life was good and I had every reason to live. I was willing to do whatever was needed. I got measured up for the operation; they couldn't seem to make up their mind where to put the stoma.

A friend gave me Chris Woollam's book *Everything you Need to know about Cancer*. I took supplements to help me through the

chemotherapy, and started Tai Chi for exercise and calmness. Keeping Calm helps, but chemotherapy does not exactly make you lively. And, I suffered from the usual side effects plus some nasty blisters that refreshed the parts of my body that other beers cannot reach. So I had a bit of a John Wayne walk in and out of the hospital during treatment.

The stoma nurses were great. They taught me how to manage my stoma and gave me a great deal of support and information afterwards including a leaflet on the **Colostomy Association** and Delivery Services.

Six months later I was preparing to go back to work. I was surprised how quickly you recover once the chemo is stopped. The university was very good in helping me back to work. I met with the occupational health people and they made sure I knew where all the disabled toilets were and that bins were provided.

Now my main problems were obtaining insurance for holidays, handling the disposal of bags and watching I did not strain my stomach whilst sailing or doing Tai Chi. And, of course, there was: "what do I do about being naked on holiday?"

I found some proper travel insurance through the **Colostomy Association's** website. At a CA Open day at Portsmouth Football Club, I discovered flushable pouches which meant I could stay environmentally friendly and use a normal toilet. I also ordered a stoma support garment.

What did I do about going naked? My wife made up some fancy colourful pouch covers, but the best solution was a plug! I

could go swimming and felt it looked better than a pouch.

Ten years later, where am I?

In 2008 I lost my youngest daughter through cancer and in 2010 I lost my wife with it too. My late wife, Millie, did not like sailing but said she would like a Viking Funeral so my sailing mate made a model one and we gave her a good send off. My daughter Julia is remembered by her motto **LIVE LAUGH LOVE**. So I try to live up to it.

I recently launched a new Online Business and Personal Development Site, **Sage Saffron**, and it was on the Internet I met my new love. Pauline, 15 years younger than me, accepted my colostomy, my naturism, my beard and my sailing. So I still sail but have a bigger boat. She just didn't like my hair, so she cut it short with a No. 2 setting. Nor did she like my clothes so she threw them all out and dragged me round Fat Face and Calvin Klein. I still travel, and we had Christmas in La Palma as it was our honeymoon...and I am still alive.

What have I learnt?

The CA has been a great help. **Tidings magazine** is full of ideas and information. Volunteering showed me there is always someone worse off than you. Suppliers also help a great deal and their staff work hard to provide a good service.

The experience has taught me that our health system does its best under difficult circumstances. Attitude is key – If you think you can, you can, if you think you can't, you won't. Try to Live each day to the full; there might not be a tomorrow!

I am sure our heroes on the battlefields would have preferred a colostomy to a coffin. Today, many survive battles even though they have lost limbs or have other disabilities. So if they can get on with their lives and contribute to the community – so can I.

Trevor Andrews



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In his article Trevor mentions the plug; what is it?

The Conseal plug mentioned on page 29, is an additional method that can be used to assist in the management of your colostomy.

It is very easy to use and can give you great freedom and control; you do not have to wear a pouch all day if using the plug. More importantly, the plug is very discreet and can be used either as a part of your daily routine or selectively as your activities vary throughout the day. The plug is a soft foam 'bung' which is attached to a flange. The bung is inserted into the stoma, where it expands, thus preventing faeces from leaving the bowel.

Who can use the plug?

The plug is designed for those who have an end colostomy and who produce a regular solid stool. If you are unsure then please contact your stoma care nurse to discuss this further. Your stoma also needs to be less than 45mm; this is due to the size of the flange. The plug is not suitable if you have an ileostomy or a urostomy.

How long can it be worn for?

This depends on your normal bowel pattern but it can be worn for between 1 and 24 hours. Ideally it should be inserted into your colostomy after a normal motion has been passed and removed when it is

anticipated the bowel needs emptying. To start with it is usually worn for short periods and the wear time gradually increased. If you have a regular bowel movement you may use the plug for up to 12 hours. If you irrigate you may be able to wear it for longer.

Does it have to be worn regularly?

Many people wear the Conseal plug for short periods e.g. when swimming, exercising or for intimate moments.

Will the plug ever pop out from the stoma?

No, the adhesive flange will keep it securely attached to the area around your stoma.

Initially, the plug can be pushed out of your stoma; this is simply because your bowel is not used to the plug. As you relax, and get used to the plug, this will usually stop happening.

What if I have diarrhoea?

If you have diarrhoea you should remove the plug and use a pouch until you are back to normal.

How can I obtain the Conseal plug?

The plug is available on prescription. If you would like to find out more about it consult your stoma care nurse.



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Breakaway Foundation introduces Family Information Days

The Breakaway Foundation was born out of a desire that no family with a child with bowel/bladder dysfunction should ever feel alone.

From those first few families that came together back in 2006 we have seen Breakaway reach out to so many families across all four corners of the UK. As soon as we received that first phone call from a scared and worried mum we knew we had done the right thing, and that mum is now one of our volunteers, offering help and support to others, showing them that there is light at the end of the tunnel.

Our telephone support has been a key part of what Breakaway offers to families, that friendly ear when things are difficult, but also the joyful ear when things go well and you just want to share the news with someone else who understands. After all your friends can never really understand the happiness that comes from hearing about a successful washout after a few days of struggling.

The Breakaway Foundation is here for the good times as well as the difficult times, and over the last six months we've been busy building up our team of volunteers, so that we are ready for the exciting projects ahead. All of our volunteers have a personal connection to bowel/bladder dysfunction. They are either a parent of a child, have a stoma

Having twins was hard enough, but when one of them was diagnosed with bowel problems things became so much harder. I was so worried about the impact that endless hospital appointments and admissions were having on my other child. In desperation I rang Breakaway one night, and not only did they listen to my sobbing, but they asked one of their volunteer mums to ring me, a mum of twins! I can't tell you how much that helped me.

themselves, are 'ex' Breakaway kids who are now over 18, or are professionals working in the world of stoma care or paediatric urology. They've all completed a one day volunteer training course, covering things such as listening and telephone skills, and all of them have a current Disclosure and Barring Service (DBS) check. Even our Patron, Mr S Nour, who recently retired from his Consultant Paediatric

We were devastated when we found out that our son had the genetic condition Currarino syndrome, there was so little information out there and most of what we found was dry and technical and all I wanted to know was what it would mean for us as a family. Someone sent me a link to the Breakaway website and I was dumb struck to find details of a family with children just like ours. I rang Breakaway and they put me in contact with them, I'll never forget the feeling of finally being able to share my fears with someone who really truly understood.

Surgeon post at Leicester Royal Infirmary, took part in the training course, and was one of the most enthusiastic in the room!

Our volunteers have first hand experience of living with all kinds of bladder/bowel dysfunction, from using Peristeen, self catheterisation, ACE, Mitroffanof, Colostomy, Ileostomy, Internal Pouch, Vesicostomy, Nephrostomy, you name it we've been there and got the T-shirt as they say. And it's not just the experience of living with a stoma, our volunteers know what it's like to be told your child has Hirschsprung's, your child has cloaca, or cloacal extrophy, or Currarino syndrome. Those words that turn your 20 week scan, or the first few hours after your baby's birth into a blurred nightmare, where Dr Google really isn't your friend.

Our helpline was relaunched on the 19th of May, reaffirming our commitment that the Breakaway Foundation is dedicated to families, dedicated to support. Our team of trained volunteers are ready to offer support and guidance at a time when it is needed most. For anyone reading this who would like to be put in contact with someone who really understands please call us on 01283 240 253 or email us at:

info@breakawayfoundation.org.uk



More information about Breakaway Foundation.	Donate online via: http://www.justgiving.com/breakawayvisits	Write to us or send a donation to: Breakaway Foundation PO BOX 7982 Swadlincote DE11 1FB	Telephone: 01283 240253 Email: info@breakawayfoundation.org.uk Web: www.breakawayfoundation.org.uk
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Medikidz: Explaining Stomas to Children

Adjusting to life with a stoma can be a challenging time for patients and their families. There are many issues and lifestyle modifications to consider, and explaining a parental stoma to children in a way that they can understand can be very difficult and stressful for families.

The Medikidz have the answer.

Medikidz is the world's first medical education company for children. Using a gang of five larger-than-life superhero characters, each representing a different area of the human body, Medikidz produces comic books to explain conditions and health issues to young people in an accessible and empowering way – think Marvel meets medicine!

A wide range of titles are available covering conditions that affect children or their loved ones, from Asthma, to Bedwetting, to Parkinsons, to Multiple Sclerosis. In fact, there are currently over 80 peer-reviewed titles published, in 30 different languages, with a list of over 300 titles still to produce! To date, over 3 million comic books have been distributed globally, helping children in 50 countries worldwide.

Medikidz Explain Stomas is the world's first book of its kind to explain parental stomas to children. The star of the book is 10 year old Selina, whose father has just had stoma surgery in hospital. Selina is worried and embarrassed about her Dad's stoma, and is afraid that they won't be able to go swimming together anymore and that people will notice an odour or leaks. Luckily, the Medikidz are on hand to help! The superheroes take Selina to Mediland, a planet shaped like a human body, to help her understand her Dad's stoma. They show Selina

the intestines, and how a tear or blockage can mean that stoma surgery is necessary. The Medikidz also talk to Selina about how a stoma works and reassure her that the bags are specially made to avoid odour and leaks, and



that her Dad will get used to his stoma care and he won't feel any pain. Selina is reassured that in time her Dad will be able to do almost everything he could do before, including going swimming!

The Medikidz also explain to Selina that a stoma may be permanent, or may only be temporary to give the intestines a rest and allow them to get better. With Selina, they also discuss how she can help to support her Dad by being understanding and showing him that she still cares about him.

Medikidz Explain Stomas has been produced in association with Dansac. The book was written by doctors, and reviewed by leading healthcare professionals using the most up-to-date science. **Medikidz Explain Stomas** is also endorsed by Ostomy Lifestyle with support from the Paediatric Stoma Nurse Group (PSNG) and the Colostomy Association.

Dr Kate Hersov, co-founder and UK CEO, explains: *"Medikidz was founded out of a frustration with the lack of child-friendly health information available. By working in partnership with Dansac, and thanks to support from Ostomy Lifestyle, PSNG and the Colostomy Association, we are aiming to reduce children's anxiety and fear by helping them to better understand the stoma of a family member."*



YOUNG OSTOMATES MEDIKIDZ

Research into how children understand critical illness has shown that children and young people assimilate information in different ways - and sometime make false assumptions which could have been avoided had information been presented in a simple, yet engaging, way. **Medikidz Explain Stomas** aims to change all of this, and is available through your Stoma Nurse. For more information about Medikidz, please visit www.medikidz.com

What do the kids think?

My mum asked me, my eleven year old brother and four year old sister to read, **Medikidz Explain Stomas** because my grandma has a stoma.

After reading the story with my siblings, I could see that they were interested in the story and information that they were given. The book contains language that is easy to understand for children of a young age without including the difficult terms that are used at school. Both of them were able to describe the condition after reading the story, which proves that the book serves its purpose to inform young readers.

I think that the comic book style drawings help to catch the attention of kids because they are similar to the kind of pictures that they would see on popular TV shows and in books. The characters were also similar to the ones that are shown on TV and were easy to relate to which made the book appealing.

My mum, who is a biologist, only had one problem with the book, and that was the fact that there were strange, yellow anteater-like creatures pushing around wheelbarrows and shopping trolleys full of poo in the background!

Overall I thought that this book was effective and is something that my brother and sister will read again.

Review for CA by Katrina

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Facebook Meet – Lancaster May 2014



Sarah writes: I am physically and emotionally exhausted, but I have the biggest smile on my face.

I have just returned from the latest CA Facebook (FB) group meet and couldn't be happier. I still get incredibly nervous about these events, even though this is the fourth one we've organised. I will be meeting new Facebook friends – what if they don't like me? And I will be seeing lots of old friends too – will they notice I've put on weight? But within minutes I've forgotten all about these worries and we are laughing and having a good time.

By popular demand, this meet was arranged in a more northern location. Lancaster was chosen, as it is home to 'Flexible Medical Packaging' (FMP) - a subsidiary of CliniMed (Holdings) Ltd. They specialise in medical and pharmaceutical packing solutions, formulation services and packaging design. For you and me, the ostomate end user, they produce silicon products, such as barrier wipes, sprays and adhesive removers that many of us use. FMP were the first to invent and develop this range of products especially for the stoma market.

A few of us travelled up on the Friday night, me after a busy few days at the CA office



and I was greeted by fellow FB Admin Steve Clark and a beer waiting for me. THAT'S the way to start the weekend!

Saturday lunchtime was when the official meet was to begin. We had been blessed with a beautiful sunny day so we all met up in the hotel garden for a drink. Friends new and old chatted, laughed and tried to avoid Steve Clark videoing their every move! I think we even managed to get FB Admin Ian Jackson to smile on a few photos!

Frances Chalmers from Clinimed Ltd who were our hosts opened the meeting with a short introduction to FMP also outlining the plans for the afternoon and evening, we were then loaded onto a bus to transport us to the factory. I was a bit disappointed there was no singing on the way, but given the heat of the day we were all just relieved to step off the bus after the short sticky journey.

Now, what to expect at the factory – I must admit I didn't think there could be much to see. In fact it was really interesting – we were split into small groups and had a tour of various parts of the factory.

Staff had come in just for us, so we could see things in action. I might be showing my age, but as a child of the 70's it was just like going through "the round window" to see how the production line worked. The FMP staff explained all as we went round and I

have to say I was surprised how much I enjoyed it.

Back onto the bus, we headed back to the hotel. I did suggest an ice cream stop but we thought queuing for 40 ice creams may take a little long!

Once back, we heard from CliniMed and FMP staff about new developments which are coming our way in the near future. I could tell you but I would have to shoot you! No, really they weren't giving away any secrets but there do seem to be some great new products in the pipelines – I'm sure Tidings readers will be the first to know when they are available.

We also had an interesting presentation from Frances about the history of CliniMed and the interaction of the companies which unraveled some questions around the





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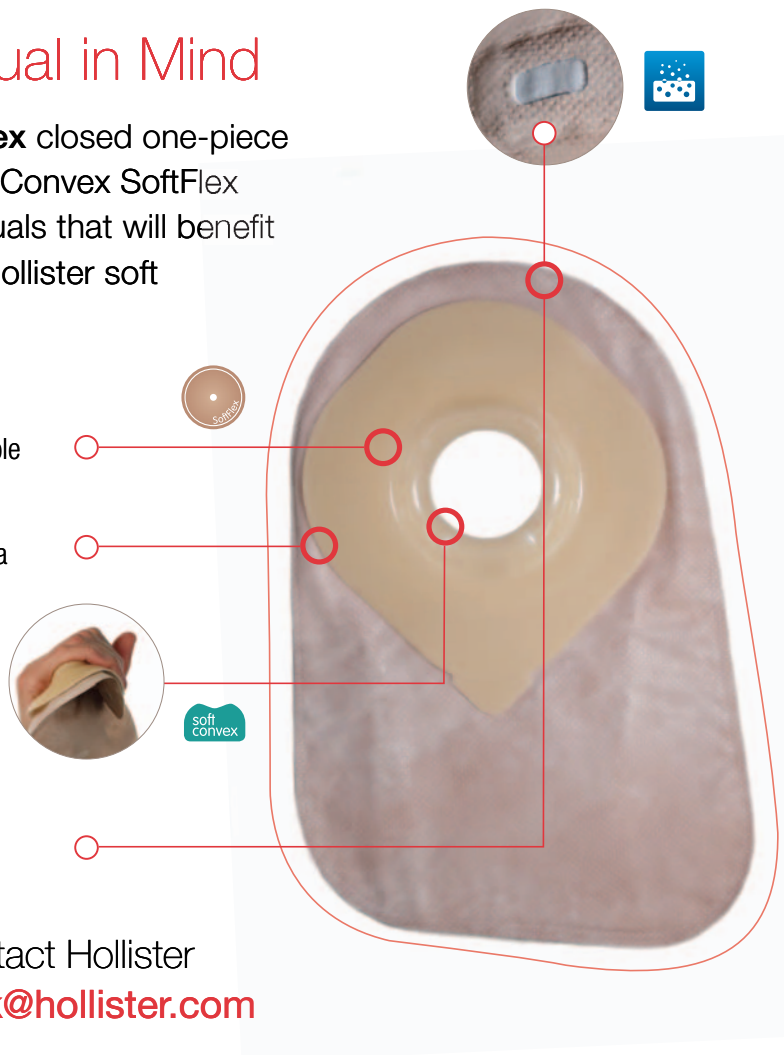
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relationship between the Group companies, CliniMed, Securicare and Welland.

By now the FA Cup Final had kicked off and certain members of the group were keen to retire to the bar, so after a few group photos we broke for a while before dinner. A snooze later (for me) we met in the bar and then went through to dinner. Ooh my word, did we get the wrong room? It was like entering a wedding reception. We weren't disappointed with the dinner served either and many more laughs and friendly banter was heard around the room. Group member Pauline Morgan had suggested a

their day trip out in The Lakes while mum "worked" in her CA role, I had planned to park them elsewhere with a bar meal, as it was really an adults event, but CliniMed kindly invited them to join us. Well, all I can say to those present is, more fool you for falling for the fluttering eyelashes of an 11 year



old who went round with her entry form and said "Which baby are you?" Yes, the prize came home with us, and Maddie is thrilled with her new mug – thank you Pauline.

We also had a simple "guess the bonus ball"

couple of little fundraising competitions. A "Guess the Baby" game certainly showed who was competitive. Twenty two of the people there had submitted a photo of them as a baby – a donation to the CA got you an entry form and Pauline kindly donated a prize. I am a bit embarrassed to announce the winner. In the absence of my "CA husband" Duncan, who is on a sabbatical at the moment I took the long suffering, real husband, Steve to Lancaster with me. Our son Ollie is studying for AS Level exams so stayed at home but we had to bring along 11 year old Maddie. After

competition. Pay a pound to guess the number then the winner gets half the money after the Lottery draw on Saturday. A huge thank you to Jan Ellis who donated her winnings back to the CA. Prize gardener Gillie Gordon and hubby John auctioned off a beautiful hanging basket, raising a further £50 for the CA. The only condition was that the winner didn't enter it into a competition against Gillie herself! Many thanks to those who contributed, and along with some people who kindly donated their deposits for the event back to the CA, we raised a brilliant £250 for the CA. Thank you all.

As has become tradition at these Facebook meets, the evening turned into early morning and friends were still chatting – and a little dancing on chairs this time too! I include the CliniMed and FMP representatives in the term "friends" too, as they were so lovely - I hope they enjoyed themselves as much as we did. By having a sponsor for an event like this it enables some people to attend who otherwise may not get there. Face to face meetings like this can be the first time someone has met another ostomate and laughs aside I feel it is a great opportunity to get to know others going through similar issues to you. Partners too find it of great benefit to meet up and talk things through.

The CA Facebook group really is an inspiring place to hang out. Members are always willing to help out those in need, and do so in such a friendly way – we really are a family. I would encourage people to join not just for advice, but for friendship and a lot of laughs along the way. On behalf of fellow admins, Natalie Slow (who sadly was

unable to make this meet – but will hopefully be there next time), Steve Clark Ian Jackson and I, would like to formally thank CliniMed, Frances Chalmers and colleagues and FMP, Chris Goodall and colleagues for an incredible weekend and also thank the CA Facebook group members for making the group so amazing. I am very proud to be part of it.

If you would like to join the closed CA Facebook group, search "Colostomy Association" on Facebook, choose the group and click the "join" tab. One of the admins will add you to the group as soon as they spot you waiting. We look forward to seeing you there.



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

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

40th Birthday Fundraiser



Kerrie Bradley turned 40 last year and decided to raise funds for the **Colostomy Association** in recognition of the support we have given her mum, Valerie (pictured here with Kerrie in the centre and

CA Trustee, Sarah Squire, right). Valerie had noticed symptoms of Crohn's disease about 10 years ago and was diagnosed in 2005.

For 5 years the Crohn's was kept under control with steroids but by 2012 Valerie wasn't at all well and was becoming very thin. After a very miserable Christmas with her family, Valerie was finally admitted to hospital on New Year's Eve 2012. The drug trial she had been involved with was instantly stopped and it was very quickly decided that stoma surgery was the only option. The surgery went well and after a couple of complications (mainly due to Valerie's ill health prior to surgery) she was discharged in January 2013. Valerie is delighted with her stoma (affectionately named *Stella*) and she's feeling the best she

has felt for many years; she's gained weight and confidence. Valerie says: "I'm enjoying a great life with my family; husband, daughters and three grandchildren. Kerrie's friend, Sarah Squire, has been such a great support for me, always on the end of the phone if I need help. I would like to thank her and the CA very much."

Kerrie says: "My dad, my sister, Kirstine, and I are so delighted to see mum looking and feeling so very much better. We had all become so desperately concerned for her health. As my milestone birthday was approaching I decided to do something for the CA to mark this.

I set up a **Just Giving** webpage and invited my party guests to donate instead of buying me a gift for my birthday. My sister and I also decided to hold a raffle on the evening of the party and combined with that, collection boxes and the online page I am delighted that over £450.00 has been raised." A special thank you goes to Kerrie, as well as her family and friends for their generosity.

Cornish Talks

Katie Sainsbury kindly **donated £45.00** having given two talks on a topic close to her heart – "Roses from the Heart" – a worldwide project to commemorate the lives of 25,556 women who were transported from the UK to Van Dieman's Land (present day Tasmania) and New South Wales between 1788 and 1853. Thank you Katie!

Bowls Match Fundraiser

Mr T Smith of Erewash Indoor Bowls Club has now organised several bowling tournaments to raise funds for us.

In April this year his club **donated £100.00** and they all had fun doing so!

Many thanks everyone, particularly as your club featured in our Spring edition having **raised £50.00** at Christmas too! It's very much appreciated.

Passionate supporter

Annie Beynon, aged 72, held a 10th birthday party for her stoma, called *Henry* in early April.

She says: "Without *Henry* I would have gone to the pearly gates a long time ago so I wanted to celebrate the 10 more years I've had here. I'm extremely grateful for the medical care I received over the 18 months after my operation and I'm also indebted to my friends at church who saw to my every need whilst I recovered at home.

"Over 50 people crammed into my flat to celebrate with me and we **raised £484.00** from the collection boxes that were displayed. Friends brought food, flowers and plants and I had enough chocolate to last for a few weeks! To say I was overwhelmed would be an understatement! Thank you for the articles and letters in the magazine, they've been a lifeline to me. God bless you all for your hard work." Thanks Annie.

Eight Mile Run

18 year old Adrienne Casso ran 8 miles in April and **raised £141.25** to thank us for our support after her stepfather, Richard Jones, had a colostomy.

Adrienne says: "The run went really well. I'm so grateful for all the support I received from friends, family and the CA's wonderful admin team. The run was inspired by my stepfather who was given a colostomy when I was aged only 13 – five years ago. At that time, my stepfather was taken into intensive care for two months and in that time he had over 8 surgeries due to severe problems with his bowels.

The most difficult part of that time in my life was seeing the strongest man I've ever known wasting away in a hospital bed. Those two months were heart-breaking and extremely challenging for my mother, my little sister and me. We were unsure if he was going to make it through and it was devastating to think about what life would be like if he wasn't there.

We knew there was a chance that he may not recover but, despite this, we put all our faith in him. We didn't stop believing.

Fast forward five years and my stepfather has made a miraculous recovery. I feel extremely blessed to still have him in my life and there isn't a day that goes by that I don't thank God for my stepfather's life. If he hadn't recovered, I'm not sure what I would have done.

He still has his colostomy and always will. I know that sometimes having a colostomy and the scars on his stomach can make him feel insecure but, to me, he is still the most beautiful, inspiring man I have ever known. You guys do an amazing job and make a massive difference to people like my stepfather. All the love in the world to you."

Adrienne, it's our greatest pleasure to have been of support to you and your family. We're all delighted your stepfather has made a full recovery. Thank you.

Thank you everyone for your kind donations

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

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

For the sum of £24 per year, you will be entered



into a quarterly draw for cash prizes of up to £500, £250, 3 x £100, 3 x £50 and 3 x £25.

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

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

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

500 Club March 2014 Draw Winners!

Mrs M Sweetland	£ 322.00
Mr A V Morris	£ 161.00
Mrs E J Barratt	£ 64.40
Mr D Brazier	£ 64.40
Anonymous	£ 64.40
Mrs J Robinson	£ 32.20
Mrs E Unwin	£ 32.20
Anonymous	£ 32.20
Mr W Hughes	£ 16.10
Mr R Harding	£ 16.10
Anonymous	£ 16.10

NOTE:

Mrs E Unwin - donated £10.00 back to the CA; Anonymous - donated £16.10 back to the CA; Mr AV Morris - donated £11.00 back to the CA; Mr W Hughes - donated £16.10 back to the CA.

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

Photo ID Card

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

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

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

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

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

Please allow 10-14 days for delivery – thank you

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

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

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

National Key Scheme - Key and photo ID card purchase

Title: _____

Name: _____

Address: _____

Postcode: _____

Tel: _____

Email: _____

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

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



Please **tick** as appropriate:

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

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

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

**Please remember to send your letters and donations to our new address:
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Specialist Nurse Education: is it important?



Pat Black, Senior Lecturer at St Mark's Institute of GI Nursing tells Tidings about:

The Dansac Academy for Specialist Nurse Education that is part of a tripartite partnership which includes Birmingham City University and St Mark's Institute of Gastro-Intestinal (GI) Nursing education.

Twelve years ago, Dansac had the foresight to make a long term investment in education in a partnership, to provide and support stoma care nurses throughout their career. Many of you will have had colorectal surgery and, for some, this may have also resulted in a stoma. You would have had the input of a colorectal specialist nurse and/or a stoma care nurse. For many of you the stoma care nurse is still an important lifeline for you even though it may have been many years since your surgery. Without the huge investment of advancing education for specialist nurses, stoma care nurses would not have had the education that many other health services in the world envy.

Birmingham City University Faculty of Health is one of the largest health faculties in the UK with more than 7,000

students enrolled. It forms the University's largest faculty. It has a proven record for graduate recruitment, and is the region's leading provider of qualified staff for the NHS and social care professions.

St Mark's Hospital, Harrow, will be familiar to many of you and is known as a centre of excellence in bowel surgery. Referrals are made to the hospital from anywhere in the UK and the world. Within the academic institute there is teaching and research for both doctors and nurses. So with this strong partnership, Dansac is the only provider of post registration education for stoma and colorectal nurses in the UK.

Courses are offered at the following levels: Diploma; BSc; MSc.

Master Classes are also available in:

- fistula care;
- ileal – anal pouch care;
- sexual rehabilitation after stoma surgery;
- stoma siting; and
- dermatology in stoma care.

These can be used as a pathway for a BSc in stoma care from 2015.

All courses and Master Classes are accredited by Birmingham City University and undergo a rigorous and robust examination before accreditation.

Also available is the course for Health Care Assistants (HCA) that is accredited by City and Guilds and gives the HCA who is interested in stoma care, a

qualification that can go with her / him throughout their career.

Courses are always highly sought after and have a continual waiting list. We currently run each course once a year. Many may think 'how nice' to go on a course and meet others with the same interest, but that is not all that it is about. There is set work that has to be completed within twelve weeks of the course or Master Class. This is marked and graded by the course facilitator and then moderated through the university before credits can be awarded. All applicants that apply need to be able to show that they have the ability to complete the required work at the level they have chosen and they need a supporting letter from their line manager to this effect.

Nurses from Europe and further afield can apply. The University operates a European Credit Transfer System that gives credits to the European nurses and allows them to work across Europe and use their credits in the same way as their UK counterparts. To date we have had nurses from Northern and Southern Ireland, Shetland Islands, Denmark, Switzerland, Romania and a doctor. All these courses are open to all healthcare professionals whether doctor or nurse.

Courses are never stationary; they continually evolve. Through St Mark's Institute of GI Nursing in partnership with Birmingham City University there will be more courses appearing over the coming months, and many of these will be able to be used with a pathway to a BSc or MSc.

Pat Black

"Education is the most powerful weapon which you can use to change the world." Nelson Mandela





Dear Reader

The Tidings team thought it would be good to run a series of medical articles about topics which may be of interest to our readers. We are going to start with a topic very close to my heart.

I had my colostomy almost seven years ago due to a rectovaginal fistula which proved very tricky to repair. Fistulas can be horrible to live with but often poorly understood. Jennie Burch, Enhanced Recovery Nurse at St Marks Hospital, explains...

Sarah Squire x

This is a short introduction to a fistula (plural fistulae) which luckily is rare. There are several types of fistula and these are fairly different from each other; this article will address mucous fistula, enterocutaneous fistula, bladder fistula, vaginal fistula and perianal fistula.

What is a fistula?

The technical term is a join between two epithelial surfaces. This can include bowel (intestine) to skin, bowel to vagina or bowel to bladder. Technically the hole where an earring goes is also a fistula, but these are there by design.

Mucous fistula

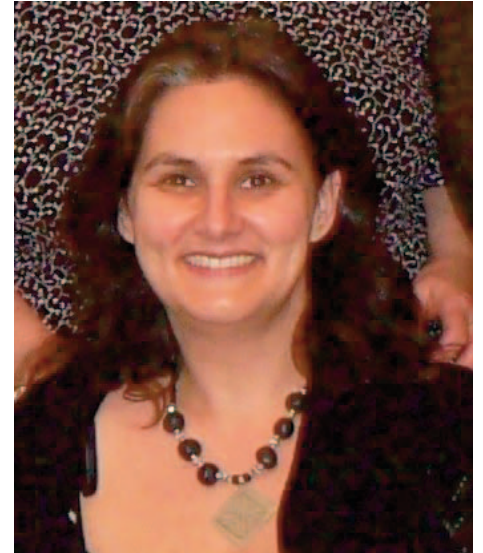
A mucous fistula may be formed during a stoma operation to make subsequent reversal easier and/or to allow mucus to drain from the redundant part of the bowel. However, these are not formed very frequently these days. Often the appearance of a mucous fistula is the same as a stoma, namely pink and wet. The mucous fistula will instead of passing faeces, pass mucus. The mucous fistula is often formed from the top of the rectum (the back passage). Mucus is produced to lubricate the passage of the faeces as it moves along the bowel towards the anus. The small amount of mucus that the redundant part of the bowel still makes, can be passed down out of the anus;

sometimes it can come out through the mucous fistula or even be reabsorbed. There are many ways that a mucous fistula might be formed. The surgeon might choose to attach it next to the other stoma (this might also be called a double barrelled stoma), the mucous fistula might be stitched onto the bottom of the cut on the tummy (laparotomy wound) or it might be somewhere else on the tummy (abdomen). As there will be mucus potentially coming up this stoma without warning it is usual to wear a small stoma cap over the mucous fistula to collect any mucus. Some people pass mucus daily, weekly or randomly, whereas some people rarely pass mucus. It should be noted that the mucus can be slightly stained with faeces as it comes from the bowel and it can smell, but as it is collected in a cap no one should notice it unless the stoma cap is being replaced. The care of a mucous fistula is similar to the care of a stoma. The skin around the mucous fistula should be gently but firmly cleaned and the cap replaced as necessary, at least once or twice weekly. Your stoma nurse can help with any further queries that you may have on the topic.

Enterocutaneous fistula

This is a rare fistula and is more common in people who have undergone surgery, and faeces come out via the wound or drain

Fistulae explained



site. It might be that this type of fistula will heal on its own, particularly if the faeces come out of a drain. However, often people with an enterocutaneous fistula have to remain in hospital and they will often need to have a special drip feed, also known as intravenous feed, parenteral nutrition or total parenteral nutrition. If there is faeces coming through the wound after an operation the usual care is to cover the wound with a big stoma bag (fistula bag), to collect and contain the faeces. This is not to be confused with a wound problem, where a wound might open on its own or be opened by the surgical team and some blood or pus comes out. In the latter situation, the wound may require dressings and possibly antibiotics if there is an infection.

Some people are well enough to be sent home with their enterocutaneous fistula covered by a fistula bag on their abdomen which they can care for themselves or have community nurses perform the bag change. Often the only way to get rid of this type of fistula is to have another operation; but this is not possible for many months, sometimes more than a year, after the first operation. It is also possible for you to go to another hospital, such as a specialist hospital, for a second opinion. Most stoma nurses have some experience of enterocutaneous fistula but it can often take a while to find the ideal way to put the bag on securely. Your stoma nurse can probably assist you with any issues that arise.

Enterovesical fistula

A bladder fistula (enterovesical fistula) can occur; this is where there is a join from the bladder to the bowel, possibly as a rare complication of diverticular disease. This might result in frequent urine infections due to small amounts of faeces passing into the bladder. This can be difficult to control, but antibiotics can help. Your GP, community nurse or urologist might be able to offer further advice to help you cope with the symptoms.

Rectovaginal fistula

There may be a join between the bowel and the vagina, called a rectovaginal fistula. This is rare but may occur for a number of reasons including trauma from childbirth (this is reassuringly very uncommon) or disease processes such as Crohn's disease. Sometimes the join may heal on its own, or in the case of a condition such as Crohn's disease medication, as prescribed by the gastroenterologist, might help. The fistula to the vagina can make it too uncomfortable to have sexual relations. Regular showers can help to reduce some of the discomfort experienced.

Perianal fistula

Sometimes there can be a join between the lower bowel (rectum) and the area between the anus and the scrotum or vagina (the perineum). This can happen for a variety of reasons including Crohn's disease but for some people the reason is unknown. Treatment can be the use of a 'seton stitch' which can help drain anything that collects so that abscesses do not form. If the cause is Crohn's disease, treatment may be medication. Advice for people with Crohn's disease can be gained from the inflammatory bowel disease nurse specialist, a GP or gastroenterologist. Care needs to be taken to keep the area clean with regular showers and possibly a barrier cream may help if the skin gets sore, but this is general advice which may not apply in all situations.

Stomas

It is possible that a stoma may be formed to control the fistula. By having a temporary or permanent stoma the bowel is diverted away from the fistula. This may allow the 'hole' to heal. Additionally diverting the faeces may improve quality of life by reducing any pain or discharge associated with the fistula.

Jennie Burch

How modern technology can aid stoma care



Jo Sica, a specialist nurse working in stoma care, explains how up-to-date communication systems can be of benefit to the ostomates she cares for.

As a community nurse specialist, I am privileged to follow patients once they have been discharged from hospital with a newly formed stoma. We all appreciate that problems can occur from time to time and occasionally there is a need for a little reassurance on life with a stoma.

With the ever increasing amount of technology on the move, many of my patients choose to communicate with me via email, SMS/Text messaging and other apps including Whatsap and Skype. I am not a Facebook or Twitter user but I know many of my colleagues are.

These forms of communication have definitely proved to be highly valuable in my practice. There are a number of examples that I have chosen to share with Tidings readers:

A man, who works in Portugal for quite extended periods of time, developed some small nodules on his stoma.

He sent me an email as he was concerned. Although he had enclosed a photograph, he actually wanted to physically show me the problem. We therefore arranged a time for us to Skype call one another and, with the use of modern technology (A webcam), I was able to watch him change his pouch and give him some tips on how to apply the pouch and check his stoma size template etc.

Whatsap is an app that is free for many SMART phone users (Although I pay the grand sum of 79p annually to use it). This is an instant messaging service and allows you to send photos directly to your Whatsap contacts.

A few of my younger patients often find it difficult to get time off work (Many are teachers). They find it more discreet to use this method of sending me a photo of their stoma or their surrounding skin and ask for my opinion. It is always important to obtain the full story as a picture can be meaningless without a full patient history.

There are of course data protection issues and patient confidentiality is paramount. Procedures regarding disposal and deletion of photos as well as recordings of conversation must be adhered to in the strictest of manner. There are laws to protect patients and Hospital and Community Trusts have policies that ensure we work with safe guidelines.

I still feel that face to face consultations will always be my first choice, but the electronic world definitely has a place in my practice.

Two years ago, I admit that I was not very enthusiastic when I was issued with a work iPhone. However, I can honestly say that it continues to prove to be a very valuable tool for a community based specialist nurse.

Dear Nurse

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



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

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

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

Q: *Could you give some advice about coping with a colostomy bag during shingles. I have had a bag since May 2005. Sometime back I developed a whopping sweep of rash coming from my spine in a thick band, down and around my waist and under my bag, with my belly button being the finishing line. I was in panic mode when I realized that the rash was probably erupting under the base-plate. A weekend. No one to speak to. I was in tears with the worry and the weakness of it all.*

On the Monday I contacted the stoma care nurse who gave me some dry powder to put on the rash which was under my bag. Against her advice I left the bag off and used a big surgical dressing and stayed at home for a few days. I managed to get antibiotics from the doctor. This made the shingles less awful but even then it lasted for eight weeks.

I just thought I'd never seen mention of shingles in Tidings so your answer may help others.

A: I'm hoping that your recent episode of shingles has now abated. It is difficult to manage a stoma if the shingles is under the adhesive as the use of creams will obviously prevent pouch adhesion. If the skin is wet then, as your stoma nurse recommended, the use of a powder will help to dry the moisture up, alternatively if the skin is dry then the use of Calamine may be of benefit to cool the irritation. Treatment for shingles should be as recommended by your GP.

Q: *Four years ago I had an ileostomy following a complete colectomy because of a haemorrhage into my colon. Alongside the ostomy is a mucous fistula which was put there to facilitate a reversal when I had recovered. On the consultant's advice I did*

rectum. It may also be worth discussing this problem with your surgeon as if the decision is made not to undergo the reversal procedure then it may be worth discussing removal of the rectum completely.

Q: *My wife had her sigmoid colostomy a year ago. Her reason for electing to have the colostomy was the fact that her anus and rectum were crudely cut during a hasty episiotomy 40 years ago to enable the birth of our second and last child.*

She has adjusted to the new routine of a stoma very well. For the first month, she was pain free. Then the anal pain returned, worse than the way it was before the operation. I know that, of course, the remaining rectum etc. still makes mucus and that some ostomates have a mucus problem including some who leak mucus too much. But my wife's problem is that the mucus never comes out on its own. Now, we learn that, most people can deal with it with some variety of enema or washout. But her defective anus is painful, and when it is annoyed e.g. with an enema, gently done, its response is to go into spasm, and lock up tight. I might add that her situation may be made much worse with her L5/S1 disc herniation pressing on the sciatic nerve, which it seems goes to the pelvic area.

not have the reversal and all has gone well until recently when I noticed the mucous fistula would swell and then partly collapse making the fitting of the pouch more awkward. This behaviour was due to gas being trapped by a ball of hardened mucus in the rectum. The blockage was removed by a relatively simple operation. Is there anything, however, that I can do to prevent this reoccurring?

A: Mucus is a natural product from the lining of the bowel to facilitate the flow of the stool through the colon. If you find that you occasionally get the feeling that you need to empty the rectum then the use of a suppository on a regular basis may help to prevent a collection of mucus occurring. Alternatively it may be worth discussing the use of a system called the Qufora Mini System with your stoma care nurse. This is a device to instil 90mls of water into the

Is there any way of dealing with a dysfunctional anus to get the mucus out, without the pain of the enema being worse than the pain caused by the mucus? We would be grateful for any advice you could provide and give Tidings our permission to include our email address ravenwatch@shaw.ca in case any readers have a similar problem and have any helpful comments.

A: I'm sorry your wife is having these problems. Removal of the mucus via the use of enemas, suppositories or a gentle washout is the normal treatment. However, as your wife has tried these it may be that you need a review by the surgeon to discuss the potential for removal of the rectum and anus completely. I hope this is sorted for your wife as I'm sure this must be a concern for her, especially when she knows she is due to perform her regular enema.

Q: I have stickers that come in the box with my bags.

(1) What are they for?

(2) How do I use them?

(3) How do they work?

(4) How do I know they have worked?

OK, I'll come clean, I have an inkling but never really found them that useful. Are you able to give me a detailed account of everything I need to know about these stickers, please?

A: These little stickers are used to cover the air filter on the pouch when you are bathing, showering or swimming. They protect the filter from water damage which would stop the filter functioning correctly.

They can also be used to reduce the performance of the filter if you have a problem called **pancaking**. This occurs when the stool cannot drop down into the pouch correctly and collects around the stoma causing potential leaks. However, if the pouch has a cover over it, you may need to uncover the filter and make sure that the sticker adheres to the filter itself. This will then allow air to remain in the pouch thereby allowing the stool to drop into the pouch.

If you have **pancaking** and using the filter stickers has not helped by themselves you can also use a gel, such as Adapt Gel from Hollister, in the pouch and also look at changing the consistency of the motion by altering your diet. I hope this helps.

Questions posted on Facebook

Q: I would like to know how someone will know if they're going to need convex flanges and how do we know how much convexity to use?

A: Convexity should only be used on the recommendation of the stoma care nurse following a review of the patient as it can cause problems if used incorrectly. There are different levels of convexity and most nurses would start a patient on a soft convexity in the first instance, moving onto stronger convexity as necessary.

Q: What are the early signs that you might be getting a hernia?

A: You may notice a swelling around the stoma which increases in size as the day progresses and if the patient is standing but then goes flat again if the patient lies flat. The size of the stoma may also increase and the patient may feel an ache around the stoma. The treatment if you notice this is to see your stoma care nurse who can assess the hernia and refer you for an abdominal support.

Replies to Dear Nurse following an answer which appeared in the Winter issue of Tidings

Dear Julie

I write referring to a question about recovering sore skin under a bag. I too had a similar problem a year ago after a trouble-free stoma for many years (13). My stoma nurse at Stepping Hill Hospital and I both felt the soreness/inflammation was caused by the moisture/perspiration caught between the bag and the body. She suggested a cotton pouch cover (on prescription from my medical goods supplier) and to be sure that my underwear was cotton only.

This has worked beautifully and I have had no more problems.

I hope that this may be of some use.

Dear Julie

Like the lady who wrote to Nurse Rust I too developed a patch of scarlet, itching skin under my colostomy bag. For five years after my operation my skin had been perfectly normal and, as the patch of inflamed skin was the same shape as my bag, it seemed to me to be the cause of the problem. I wrote to the manufacturers, who were very helpful and sent me a breakdown of the ingredients in the pouch and flange. I was tested for allergies – no reaction.

Several doctors prescribed steroid creams and after two years of using these, to no avail, my skin has become so thin that it blistered, broke open and bled.

I asked to be referred to a skin specialist. Three specialists later I was off steroids but no better. So I decided to cure myself.

In an edition of Tidings I saw a new bag advertised by a different manufacturer and sent for samples. I also changed from a liquid to a powder deodorant. Night and morning I applied Aloe Vera gel with Tea Tree oil. I have continued with the different bags and with this new regime and my skin has stopped itching, returned to its natural colour and is slowly growing back. I hope this information will help fellow sufferers.

Julie says:

Thank you for sharing your experiences as they show different things/products that people can try to manage a problem. There is obviously no single solution to all problems and the ability for patients to discuss their experiences is a valuable asset for other ostomates.

What kind of stoma do you have?

When food leaves the stomach it enters the small intestine, a long coiled tube about twenty feet long. 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 digested food passes from the small intestine directly into the large intestine or colon. 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 as necessary.

The above applies in most cases, but there can be exceptions. For example, 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. Therefore some colostomates may prefer to use a drainable bag.

Editors Comment

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

If so write in and tell us:

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

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



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Readers' writes



Rosemary would like to hear from you, learn about your experiences, and understand your concerns. Write, email or phone the Colostomy Association today!

Dear CA

I have just been reading my copy of the spring edition of *Tidings* and the article written by Rob Fearn. Like Rob, I had been having problems with diverticulitis and I was told it must be IBS. I can sympathise with Rob: trying to go out, even to do the simplest task, I would have to take clean underwear, pads, and have a good knowledge of where the nearest toilets were.

Eventually, I was admitted to hospital with what first of all turned out to be salmonella and I was referred to my wonderful surgeon at my local hospital. At my first consultation he took a very thorough case history and arranged various investigations and finally a CT scan. At my appointment to review all the results, I was told I needed to have a hemi-colectomy (removal of part of the colon) as soon as possible. I asked if this could wait a couple of weeks as I was going to Greece in the next ten days. My consultant was a little reluctant but finally agreed and gave me a letter to take with me about my condition and a prescription for antibiotics.

On my return I was admitted to hospital to have the operation and only then did it finally hit me that I was going to come out of the operation with a colostomy. I was both relieved and apprehensive all at the same time.

On coming round from my operation, the first person I saw was my wonderful husband and the look on his face was one of relief. It was not until I spoke to my consultant the following morning that I found out the full extent of my problems. I came home to a new freedom when going out, and made the decision not to have my colostomy reversed.

Due to my severe diverticulitis, five years after having my stoma, I had to have the remainder of the colon taken away and I now have an ileostomy – very little

difference except now it is on my right side. My family say that this is my designer addition.

I have never ever regretted either operation. My life is full and active. I have a lovely family and two wonderful grandchildren who have grown up with my 'bag' as they were only babies when I had the first operation. I fully understand what Rob went through for fifteen years and what it feels like to have the freedom a stoma bag gives.

Many thanks for your wonderful magazine. It helped with many of my problems when I first had my colostomy and now I have an ileostomy, there is always an answer for the little niggles that I may have.

With regards to you and your staff
H.P.

Dear Editor

It was good to read Rob Fearn's experience of his emergency operation due to diverticulitis. This happened to me in April 2011, due to a perforated colon which resulted in peritonitis, other serious complications and a stay in ITU for 11 days. I had also suffered with IBS for many years. At first I was anxious to have a reversal but was encouraged to think hard about this and way up the pros and cons. I decided to stick with the stoma.

This has been a blessing to me, as, like Rob, I could not venture far afield without worrying about where the nearest loo was. This impeded a lot on my life before I retired. Yes there are a few negatives – but generally more positives. It's great to read about others in the excellent *Tidings* magazine.

I have had my colostomy for almost three years now and have thankfully had a good experience with my supplier. The system did change a while back and after discussion with my GP it was suggested I order my prescription over the internet (maybe not everyone has this option); about 3 days later I collect this prescription

and send it to my supplier in the pre-paid envelopes they provide. I find this quicker than the GP surgery doing so. The order generally arrives two days later. I place my prescription request when I am about to start on my second box of pouches; I have always done this even when I was using more each month and it has worked very well. If no one is at home to receive the parcel the courier leaves it in our outside, unlocked, cupboard. Long may this good service continue.

P.H.

Dear Editor

Just reading *Spring Tidings* about A.B. not being able to order straight from the company she deals with. This happens to me now and I got round the problem by ordering six months' supply at a time. I just had a word with my GP and he gave the go ahead, so that when I now get to my last three boxes I re-order. This works well for me.

A.B.

Dear Editor

I order one box of pouches and two Appeel adhesive removers per month. I have a colostomy and I did not think that this was an unreasonable amount. I am going on holiday on the 2nd June for the whole of the month, travelling around Ireland. I asked my supplier (Fittleworth) if at the end of May I could double up and then not have another order until the end of July. This was in April, so allowed plenty of time.

They said I would have to tell my GP, as if a delivery company requests extra supplies they wouldn't get it. I thought no problem so made the appointment. I was told that I couldn't have two months' supply and then miss a month, the reason being that my prescription might change. I then rang Fittleworth who then said if I needed extra supplies while away I would have to use Worldwide Assist and they

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Readers' writes



sent me the leaflet. I must admit I am shocked at my GP's reaction. How to make a straight forward thing complicated. Is this the norm? If you could throw any light on this I would be grateful.

Regards
C.R.

Dear Editor

In the Spring issue of *Tidings* A.B. says the supply company now has to have an actual prescription in their hands before they can send the items requested. Well, I've had my stoma for 32 years and have the pouch holes cut to size by the supply company that provides them. The so called "new" requirement has operated in my experience all that time and has never presented a problem.

"My" supply company like A.B.'s is open only from Monday to Friday. "My" surgery also does not open at weekends. "My" courier delivers only from Monday to Friday – and always before midday. Given these limitations (and they are very common) what is the answer?

Look ahead. Don't leave things to the last moment. You should never find yourself counting your "few remaining pouches". This is a mistake you make in your early days as a colostomist, but not after 20 years.

Mine is an excellent surgery but it does need a couple of days for a repeat prescription to be produced. Once I have it, it is posted immediately to the equally excellent supply company. Nowadays even 1st class post doesn't guarantee next day delivery so, yes, it takes two or three days to reach them. They then phone me to say it has arrived and they tell me when I can expect delivery, i.e. which morning because it never fails to arrive by 12 noon.

Now, I cannot see any difficulties in this system, nor can I agree that it is "incredibly wasteful" of the patient's time. I have a supply of pre-paid pre-addressed envelopes. Into one of these I place a brief covering note (not absolutely necessary) and my prescription and pop it in the post. No phone call necessary! In practice this system works very well provided one

plans ahead, allows plenty of time and accepts the existence of non-working weekends! From start to finish one should allow a fortnight or so. My own prescription is always the same – 4 boxes of 30 pouches – and I do not wait until I am on the fourth box before requesting a repeat prescription from the doctor!

By the way the NHS ruling (which was news to me) strikes me as being entirely reasonable. Why shouldn't the providers of the medical items you require expect your prescription to be in their hands before they forward those items to you? Frankly, that's the basis on which I've always assumed I dealt with my own suppliers. After all, although we ourselves don't pay directly for our medical goods, I do know that the cost to the NHS for colostomy-related products – especially pouches – is considerable. It therefore seems sensible for a company not to part with them on the basis of a phone call – even one apparently from a long established customer - but rather to wait until they have the necessary authority in the form of a signed prescription. To do otherwise could be regarded as irresponsible.

Yours sincerely
D.S.

Dear Editor

Re. the change in dispensing rules, the new NHS rules mean we'll all have to hold bigger stocks to cover longer and erratic delivery times – do they really want that?

Instead, I suggest that A.B. (Reader Writes) enquires from her GP whether she can order repeat prescriptions online – via her Practice web site. If so, her prescription request will immediately be received by the Practice and (hopefully) approved same day; a copy is then automatically sent by email to the dispensing company (which the Practice will set up at her request), so can be received the same day as well, and they can immediately get down to work cutting and dispatching the items needed. A.B. would find it easier and in all likelihood quicker than the old system, and all without leaving home. The only drawback I've found is that the online form allows me to order only one of an item per order, i.e. one box of a particular type of pouch, though as I

use several different types in rotation to minimise skin irritation, that's not too much of a nuisance. In fact, I have a meeting arranged with my stoma nurse for next week to agree the full list of items I need from time to time, so that my doctor can update the items on the online repeat prescription form.

Surgery appointments can be set up online here as well, which is great – one can see which doctor is available at what time of the day for a week ahead before you choose a time and book it. Some changes are good!

Disposal of used Stoma Appliances – the options quoted at the end of the article omitted 'Use irrigation if you can'; rinse out the sleeve into the toilet before you take it off, and there's no bodily waste left so it can all go in the usual bin with no problems.

Finally, hats off to Ostomart and their advertisement on the back cover of Spring 2014 *Tidings* – the first time I've seen a manufacturer appreciating that we, the users, are interested in what the NHS has to pay to support us. As my GP told me: "you're one of our high-maintenance patients". Most of us recognise that, and try to minimise the cost; we've all had our money's worth from the NHS, after all.

Best regards
Paul Reynolds

Dear Editor

I am writing in reply to the letter from M.B. regarding the disposal of her used pouch.

I too, live in an area that collects household waste in two weekly cycles. I have found that using a Tommy Tippee, advertised as a disposal unit for babies' nappies, and available from Mothercare and large supermarkets, is the answer.

The Tommy Tippee is a medium sized plastic container with an insert of a plastic sleeve. It is very simple to use. The lid opens and you place the used pouch into the plastic, scented sleeve, turn the handle at least twice and seal the used pouch in a pocket that drops down into the container forming a sausage of sealed

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Readers' writes



pockets. The container can easily hold up to 24 used pouches.

I empty my container at least twice a week – cutting off the sleeve and refastening it into the container. Once the sealed pockets are free of the container I place them in a plastic carrier bag, tie it tight, and then proceed to place that bag into another plastic bag and seal it.

Once you are confident that the used pouches are tightly sealed, it is time to drop the whole package into the household waste bin. No more fears of odour while waiting for the next waste collection. I have checked with a number of councils and they are totally supportive of this way of disposal.

It does help to empty the contents of your pouch into the toilet before attempting to place it in the Tommy Tippee, but I quite understand if you do not find this acceptable.

My Tommy Tippee is kept in my bathroom, however, I know of many ostomates that keep the container in the garage or a utility room as they do not want to advertise their disposal unit.

J.R.R.

Dear Editor

I would like to pass on a useful idea to other men whose waist size maybe has increased since a bowel cancer operation, or who have a colostomy and/or hernia(s) and find it difficult buying trousers that fit properly.

I had an APR operation for bowel cancer three years ago and ended up with a right side incisional hernia, a kidney out one year later and then a left side stoma hernia. However, I am still tall/slim but now with bigger waist size. Alterations to the seat of 40" waist trousers still left them obviously too big and embarrassing for me to wear. However, I hit on Marks & Spencer trousers and chinos with "active waistband" where the elastication is not within the waistband. So, I simply cut the two accessible elastic strips each side on 36" waist trousers, effortlessly stitched up the main fabric and gained two inches

each side. I now have overall properly fitting trousers but with 40" waist and am now happier, more confident, out and about socialising with friends and no embarrassment. Hope this helps somebody.

Regards
P.C.

Dear Editor

I have read and seen a lot recently in *Tidings* with regard to Bowel Cancer Screening. Whilst I believe this is an important and a useful tool I would point out the shortcomings of this and urge your readers to be aware of them.

The reason for this is that I had some symptoms and thought I should go to the doctor but at that time I had a bowel screening kit come through the door so I refrained from making an appointment. I completed this and returned it and got my results back saying negative. So I thought I was imagining things and did nothing about it.

Several months later the symptoms got a lot worse so I went to the doctor, but too late. The cancer had spread beyond the growth into the rectum which resulted in a complete removal of the rectum etc. Had I gone to the doctor originally, this may not have been necessary.

I then discovered that the bowel cancer screening test will only give positive results if the growth is bleeding at that time, so will apparently pick up cancer in around 1 in 3-5 cases.

Please remember the test is only an indication but people should not rely completely on this test and if they have any doubts, they should visit their GP sooner, rather than later.

Best wishes
D.E.

Dear Editor

I felt I had to write to you after reading about the background of your new president, Mr Ian Daniels FRCS, in the spring issue of *Tidings*. He mentioned his training in Wales and that he'd worked with the colorectal surgeon, Mr Nick Carr, in

Swansea. If it wasn't for Mr Carr I would not be alive today.

He operated on me in June 1999 for bowel cancer – a hysterectomy and bladder repair were also carried out as I had a large tumour connecting the organs. After having a six hour operation and being taken to Intensive Care I unfortunately started haemorrhaging and was rushed back to theatre. I will never forget Mr Carr telling me afterwards that if it had been a fine afternoon he would have been out on the golf course, but as it was such a bad day, weather-wise, he was able to rush back to Singleton Hospital to save my life.

After being discharged I had three months of chemotherapy and twenty sessions of radiotherapy. I have now lived with my stoma for fifteen years. It's part of me and I wouldn't be alive if I didn't have it. It hasn't held me back in the least way and my husband, when he was alive, and I went on eight sea cruises and also out to Malaysia to visit our son and family twice.

Yours faithfully
M.W.

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

Thank you for your letters and e-mails. Please keep them coming. We will do our best to print them or we may hold them over for a future issue.

Editing may be required for reasons of clarity or space. In the interests of confidentiality we will publish only your initials and not your full name, unless you give us permission to do so.

If you want to be involved in the next issue of *Tidings* magazine simply drop us a line

via email:

editor@colostomyassociation.org.uk

or write to:
The Editor

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



Look out for our Readers' Button to see where readers have contributed to *Tidings*

Helpful Ostomy Support Groups & Organisations

- IA The Ileostomy and Internal Pouch Support Group
Freephone: 0800 0184 724
www.iasupport.org
- UA Urostomy Association
Tel: 01889 563 191
www.urostomyassociation.org.uk
- IOA International Ostomy Association
www.ostomyinternational.org
- Stomadata
www.stomadata.com
- Macmillan Cancer Support
Tel: 0808 808 00 00
Mon - Fri: 9am - 8pm
www.macmillan.org.uk
- Mitrofanoff Support
Tel: 01202 937 530
Email: info@mitrofanoffsupport.org.uk
www.mitrofanoffsupport.co.uk
- Crohn's and Colitis UK
Tel: 0845 130 3344
(Mon-Fri 13:00-15:30 and 18:30-21:00)
www.crohnsandcolitis.org.uk
- IBS Network (formerly: The Gut Trust)
Tel: 0114 272 3253
www.theibsnetwork.org
- Bladder and Bowel Foundation (B&BF)
Formerly Incontact and Continence Foundation
General enquiries: 01536 533 255
Web: www.bladderandbowelfoundation.org
- Bowel Cancer UK
Tel: 020 7940 1760
Email: admin@bowelcanceruk.org.uk
Web: www.bowelcanceruk.org.uk
- Beating Bowel Cancer UK
Tel: 08450 719 301 (Lo Call rate)
Web: www.beatingbowelcancer.org
- Gay & Lesbian Ostomates (GLO)
(The United Ostomy Association in 1982 established the Gay and Lesbian Concerns Committee, now called Gay and Lesbian Ostomates (GLO) Network.)
Web: www.glo-uoa.org
- Ostomy Lifestyle
Tel: 0800 731 4264
Email: admin@ostomylifestyle.org
Web: www.ostomylifestyle.org

Stoma Care Patient Open Day event dates

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

Listings are updated throughout year.

If you are not online contact CA on:

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

Note: The Colostomy Association full contact details can be found on Page 4.

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

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



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Ref. No. SS104

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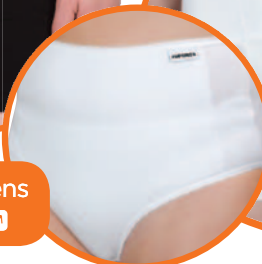


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Epsom and St Helier Stoma Care Department – Open Days –

Date:
Wednesday, 2nd July 2014
Holiday Inn
Gibson Road, Sutton SM1 2RF
1:00pm to 4:00pm

Come and meet Vicky Wilson, Charter Healthcare Nurse

Date:
Monday, 14th July 2014
Bourne Hall
Ewell, Epsom KT17 1UF
1:00pm to 4:00pm

Come and meet Lindsay Trevarthen Stoma Care Nurse

The Trust Dietician will be doing a short talk from 2:00pm at both venues

For more information call:
Epsom Stoma Care Department
01372 735 925

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Ladies Big Op Group

The meetings are for ladies who have had a pelvic exenteration and require one or two permanent stomas.

The group meets on the **2nd Tuesday of every month** at the **Maggie's Centre**, The Lodge, College Baths Road, Cheltenham GL53 7QB

Time: 10.30am – 12.00noon

Next meetings:

• Jul 8th • August 12th • October 14th
To **book** please contact:

Sam Richardson at Maggie's
email: Samantha.Richards@maggiescentres.org

Gill Hopkins Stoma Care CNS Direct line office 03004 224363 Stoma Care Office, Cheltenham General Hospital

Meetings are supported by **Gill Hopkins Stoma Care CNS, Gynaecological Nurse Specialist and Cancer Support Specialist from Maggie's.**

There is also access to a dietician, benefits advisor and physiologist should attendees require any extra help.

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

Thank you for your support

Regular donation

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

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

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

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

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

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

To the Manager: (Bank or Building Society)

Bank Address: _____ Postcode: _____

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

Account number: _____ Sort code: _____

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

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

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

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

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

Name: (IN CAPITALS) _____

Signature: _____ **Date:** / / 2014

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

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

Signature: _____ **Date:** / / 2014

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

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

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





Single donation

Thank you for your support

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

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

<p>Note: Please ensure that we have your correct contact details: full name, address, postal code and telephone number. Thank you.</p>	My Details: Title: _____ Name: _____ Surname: _____
	Address: _____
	Postcode: _____
	Telephone (home): _____ Mobile: _____
	Email: _____
Optional Information: Date of Birth: _____ Stoma Type: Colostomy <input type="checkbox"/>	
Reason for your stoma: _____ (Please tick) Ileostomy <input type="checkbox"/>	
Year of operation: _____ Urostomy <input type="checkbox"/>	
(NB: The optional information is not mandatory but will help the CA learn more about you – it will not be passed on to third parties)	

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

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

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

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

Yes, I require a receipt (Please tick).

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

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

giftaid it

Thank you for your gift

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

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

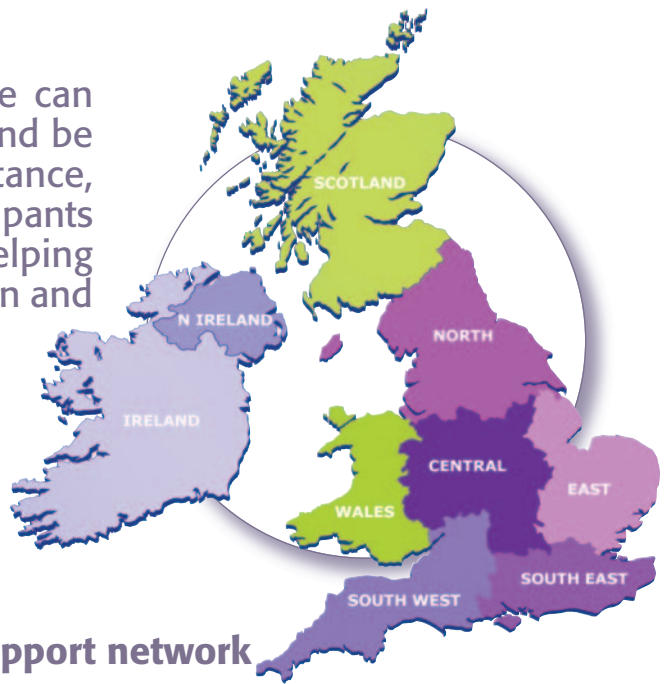
Signature: _____

Date: / / 2014

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



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.



Lancashire: Diversions – family support network

Who we are

Diversions is run by people who have, or whose children have a bladder or bowel problem. We understand your situation because we have been there.

We have the support of a number of healthcare professionals, including nurses, consultant surgeons and paediatricians.



What we do

We support your whole family by providing you with the opportunity to meet others in similar situations, outside of the hospital environment.

We deliver a fun programme of activities across the North West of England that are accessible to all. These include outdoor adventures and team building tasks, art work-shops, meals out, day trips and weekends away.

What we provide

- Free places or subsidised rates for fun activities.
- Events for your whole family to enjoy, including siblings or other family members.
- Up-to-date Stoma care information on products.
- Links into other well-established groups.

Why we do it

We want to break down feelings of isolation that you may experience on your journey and help build your confidence by learning from and sharing each other's experience, whilst having fun.



For more information about:

Diversions visit the group's website:
www.diversions.org.uk

or

contact:
Alan Dickson via e-mail:
diversions@live.co.uk

Melissa: 07816 513 889

or

Rachael: 07814 613 669



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

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

Stoma support groups in your region



Scotland

• **Ayrshire:**

Ayrshire and Arran Stoma Support
Contact: Jim 01292 220945

Stoma Care and Recovery (S.C.A.R)
Contact: Maggie 01294 271060/ 0781 7736147/maggie13@sky.com
Rhona 01294 557 478

• **Fife:**

Fife Ostomy Support Group
Contact: Ishbel Barr 01592 772 200

• **Glasgow:**

Glasgow Stoma Support Group
Contact: Maureen O'Donnel
01236 436479

G66 Support Group

Contact: Les Ireland
0141 776 3866

• **Midlothian:**

Maggie's Edinburgh
Contact: Maggie 0131 537 3131

• **Scottish Borders:**

Stoma Support Group
Contact: Nancy 01450 374012/nancyfraser@talktalk.net
Fiona 01450 371063/
r.gentleman@sky.com

• **West Lothian:**

GOSH
Contact: Scott Pattison: 07502163644



England – North

• **Cheshire:**

Stockport Support Group
Contact: Angela Simpson
0161 320 9400/0800 652 6667

TOMAS (The Ostomates of Macclesfield and Surrounding Areas)

Contact: Kath Wood 01625 875442

Warrington Ostomy Support Group

Contact: Jane Shaw 01925 662103

• **Cleveland:**

Oops Group
Contact: Julie Morrisroe SCN/Carol Younger 01287 284113

• **County Durham:**

Bishop Auckland Stoma Care Group
Contact: Betty 01388 814535

• **Cumbria:**

Grange Cancer Support Group
Contact: Marie 015395 33279

• **Lancashire:**

Oldham Stoma Support
Contact: June Wilde 0161 312 5538

Tameside Ostomisticles

Contact: Paul Seavers 0777 1359046

Trafford Bowel Care

Contact: Jackie Carey (Secretary) 0161 7489 659/Doreen 0161 9627 818/John 0161 7484 655

North Manchester and Bury Support Group

Contact: Julie Meadows (SCN) 0161 720 2815/07841206910

• **Merseyside:**

I.C.U.P.S
Contact: Stoma Care Nurse
0151 604 7399

• **Northumberland:**

Berwick Ostomy Support Group
Contact: Bobbie Minshull 07714 479320

Hexham Ostomy Group

Contact: Judith 0796 792 7286

Northumberland Cancer Support

Contact: members@northumberlandcancersupportgroup.co.uk

• **Tyneside:**

NHS Molineaux Walk-in Centre
Contact: Lesley Brown 0191 282 6308

Royal Victoria Infirmary Support Group
Contact: Gordon Weatherburn
0191 234 1109

• **Yorkshire:**

Acorn Ostomy Support Group
Michelle Hurrell on 07580 693 155
(after 6pm).

Airedale Stoma Support Group
Contact: Sue Hall 01535 210 483

Barnsley-Bottoms Up
Stoma Support Group
Contact: Stoma Nurses 01226 432 528
or Celia Utley (Chairman) 01226 284
262

Behind You (Calderdale & Huddersfield
Bowel Cancer Support Group)
Contact: Stoma Care Nurse
01484 355 062

Dales & Vale Ostomy
Support Group
Contact: Carol 01677 988 150/pcw-
agw@tiscali.co.uk

Dewsbury & District Ostomy
Contact: Janet/Eileen 0844 811 8110

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

Rotherham Ostomates
Caring Support
Contact: Karen 07880 575 758

Scarborough Stoma Support
Contact: Sister Jean Campbell 01723
342 388 Amanda Rowe 01723 342 446

The Hull and East Riding Colostomy
Support Group
Contact: Pete Smith 07989 565 335
Pete Rennard 07939 518 642/
01482 793 966/Rosanna Grimsby
01482 801 575

• **Isle of Man:**

Stoma Support Group
Contact: Carole Cringle (SCN) 01624
650 212



England – Central

• **Buckinghamshire:**
Milton Keynes Stoma Association
Contact: Mrs Joanne Dixon 01908 318
262

• **Leicestershire:**
Kirby Ostomy Support Group
Colostomy, Ileostomy & Urostomy
in Leicestershire
Contact: Janet 0116 239
2844/kosg2013@btinternet.com

• **Nottinghamshire:**
Nottingham Colostomy, Ileostomy &
Urostomy Support Group
Contact: Rosemary Brierley
0115 982 6691

Nottingham Stoma Support
Contact: Jenny or Michaela 0115 962
7736/Mrs B Heath 0115 966 3073

North Notts Stoma Support Group
(Sutton-in-Ashfield)
Contact: Tore and Nicky Norman 01773
715 460

• **Shropshire:**
B.O.T.S (Bums on Tums)
Contact: Irene Constable 01691 238
357

• **Staffordshire:**
Outlook
Contact: Moira Hammond 01782 627
551

• **Worcestershire:**
Kidderminster & District Collossus
Support Group
Contact: Brendon Drew
01299 400 843

• **East Midlands:**
Newhall Stoma Support Group
Contact: Diana Manning 01283 541 311
or Helena 07932 331 850

• **West Midlands:**
Coventry Stoma Support
Contact: Martin Robbins
07947 385 643



England – East

• **Bedfordshire:**
Saturday Social Club
Contact: Karen Richards
01234 792278

• **Cambridgeshire:**
Ostomistics
Contact: Alan Wright 01354
653290/07836 661102

• **Essex:**
Connect
Contact: Lin Hart 01279 505273

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

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

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

STEPS
Contact: Jackie Coleman
01268 451937

Redbridge Ostomists Club
Contact: Stoma Nurses: Chris/Lisa
020 8970 8321

• **Hertfordshire:**
Colonise
Contact: Anastasia
01727 760 981

Hertford Stoma Support Group
Contact: Ralda 01992 535 311

Stevenage Ostomistics
Contact: Alfred Levy 01767 316 958/
Judy Colston 01438 354 018

• **Lincolnshire:**
Friends East Coast Support Group
Contact: Betty 01205 724 120/Sheila
01205 364 493

Grantham Support Group
Contact: Bobbie/Amanda:
01476 464 822
Email: grantham.colorectal@ulh.nhs

March Group
Contact: Maureen 01754 874 485

Sutton Bridge and Long Sutton Ostomy Group
Contact: 01406 351 617

• **Norfolk:**
Kings Lynn Ostomy Friendship Support Group
Contact: 01533 691 370/768 271 or 01533 775 698

Stars
Contact: Anne Browne 01603 661 751

• **Suffolk:**
East Suffolk Ostomy Group
Contact: Marion Fisher 01473 311 204

James Pagett Ostomy Support Group
Contact: Sandra Hutchings 01502 585 955

West Suffolk & District Stoma Group
Contact: Jessica Pitt (SCN) 01638 515 525



England – South East

• **Berkshire:**
EBOC (East Berkshire Ostomy Club Bracknell)
Contact: Jackie Dudley 01344 426 652

WBOC (West Berkshire Ostomy Club Reading)
Contact: Jackie Dudley 01344 426 652

• **Hampshire:**
Solent Ostomates Support Group
Contact: Carole Summer 07527 707 069

Solent Ostomates Support Group (New Forest Branch)
Contact: Carole Summer 07527 707 069

Wessex Urology Support Group
Contact: David Morris 07910 786 978

• **Isle of Wight:**
Optimistics
Contact: Andrene Coates & Amand Broadbridge (CNSs) 01983 534 009

Semi Colon Group Isle of Wight
Contact: Tony Crowson Chairman 01983 559 326
CNS Helen Fulford 01983 534 180

• **Kent:**
Ashford Stoma Support Group
Contact: Ron Huckstep 07941 310 681/Margaret Webb 01233 628 807

Atoms Support Group
Contact: Maria Culleton SCN 01227 769 679/07827 997 424

Dover & District Stoma Support
Contact: Maria Culleton (SCN) 01227 769 679

Dover Stoma Friends Group Support
Contact: Julie Bell & Ros Marshall 07771 345 701/01304 822 696

Maidstone Stoma Support Group
Contact: Judy or Kirsty 01622 224 305

Medway Ostomy Group Support (MOGS)
Contact: Helen or Tracey 07773 605 534

Thanet Stoma Buddies Support Group
Contact: Phil (Secretary) 01843 587 769

• **London:**
Homerton Hospital Bowel & Stoma Support Group
Contact: Angela Davy 020 8510 5318

South Woodford Support Group
Contact: Christina 020 8535 6563

Surrey & South London Bowel Cancer Support Group
Contact: Sue Berry: 01737 553 134 or John Amos: 020 8668 0796

• **Middlesex:**
Inside Out
Contact: Bob (Chairman) 020 8428 4242
Sarah Varma 020 8235 4110

Semi-Colon Club
Contact: Pat Black/Katheryn Foskett 01895 279 391

• **Oxfordshire:**
Oxfordshire Ostomy Fellowship
Contact: Pat Longworth 01235 524 163

• **Surrey:**
Epsom & District Stoma Support Group
Contact: Lindsay, Trevor or Sheena 01372 735 925

• **Sussex:**
Colonaïd
Colorectal Dept at Worthing Hospital
Contact: Andrew Fletcher e-mail: colonaïdworthing@yahoo.co.uk

(SAS) Brighton & District Stoma Care support
Contact: Sylvia Bottomley 01273 554 407

The Ostomy Friends Group
Contact: Jane Quigley 01323 417 400 Ext 4552

West Sussex Princess Royal Stoma Support
Contact: Tina Walker 01444 441 881 Ext 8318



Don't forget your travel certificate this Summer

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



England – South West

- **Avon:**
B.O.S.S Bristol Ostomy Self Support
Contact: Rob 0117 966 8021/Janet
01934 248 114
 - **Cornwall:**
Ostomist and Carers Support Group
Contact: Christine Davey
01208 831 471
- Optimists
Contact: Sue Hatton 01326 340 058

- **Devon:**
Mid Devon Ostomy Group
Contact: Janice Parkyn
01363 776 417
 - **Dorset:**
CUPID Colostomy, Urostomy, Pouch, &
Ileostomy of Dorset
Contact: Beryl Andrews
01202 483 303
- CUPID Colostomy, Urostomy, Pouch &
Ileostomy of Dorset - West Dorset
Contact: Colin Clare
01305 853 288
- **Wiltshire:**
Swindon IA
www.swindon-ia.org.uk
- Wessex Stoma Support Group
Contact: Michael Slater 01722 741 233



Wales

- **Gwent:**
Blaenau Gwent Self Help
Contact: Celia McKelvie
01873 852 672

- **Bridgend:**
Bridgend Ostomy Patients
Support Group
Contact: Anita Brankley (Secretary)
01656 645 602 or Pat Jones 01656 786
103

- **Newport:**
COSG (Cwmbran Ostomy Support
Group) Contact: Pippa Lewis 01633 791
339/07504 713 069

- **Mid Glamorgan:**
Royal Glamorgan Stoma Care
Support Group
Contact: Domenica Lear
01443 443 053

- **Swansea:**
Swansea Ostomy Self Help Group
Contact: Glynis Jenkins 01792 418 245



Northern Ireland

- **County Antrim:**
Antrim Area Stoma
Support Group
Contact: Chris Wright
07720 717 771
- Mater Infirmorum Hospital – Belfast
Contact: Karen Boyd
028 9074 1211 Ext 2329
- Royal Victoria Hospital – Belfast
Contact: Sarah Haughey/
Audrey Steele 028 9024 0503
Ext 3483

- **County Armagh:**
Craigavon Community Hospital
Contact: Mary Jo/Bernie
028 3861 2721

- **County Down:**
Daisy Hill Hospital – Newry
Contact: Bernie Trainor
028 3088 3500 Ext 2222

- **North Down Stoma
Support Group**
Contact: Adrian Ewing 07850 741 511

- **Ulster Hospital**
Contact: Hazel/Martina
028 9055 0498

- **County Londonderry & Derry City:**
Causeway Patient
Support Group
Contact: Mary Kane 028 7034 6264



The Channel Islands

- **Guernsey:**
Guernsey Ostomates
Contact: Luci Deane 01481 236 077/
lucideane58@gmail.com



Eire

- **Bowel Cancer Support Group
(Irish Cancer Society)**
National Cancer Helpline
Freefone: (00 353) 1 800 200 700
Contact: Olwyn Ryan
(00 353) 1 231 0500

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

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

Contact the **CA office:**
0118 939 1537

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



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