colostomy association

Tidings

Spring 2007 Issue 5

Dedicated to Colostomates and their Carers

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Tidings
Dedicated to Colostomates and their Carers

The Colostomy Association is a charitable company limited by guarantee (Registered Charity No: 1113471) that 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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inside
this issue of Tidings

Dear Readers..

When we were considering what to include in this issue the editorial team studied your answers to the questionnaire we sent out in issue 3 and the suggestions you made for the articles you would like to see in Tidings. Contributions from stoma care professionals are popular so this time we have articles on skin care and also diarrhoea - two of topics you mentioned - written by nurses.

While you find it interesting to read of other colostomates’ experiences, you told us that articles about holidays should focus more on coping with a colostomy while travelling rather than the places visited. So with this in mind our centre pages focus on finding insurance cover, getting your supplies through customs, and hints and tips for managing your stoma while away from home.

Many readers asked for more information on new stoma care products and services. In response to this, we are introducing a new regular feature entitled “Update” in which we invite manufacturers and suppliers to tell us about their latest developments.

We were delighted with the number of entries we received to the Name your Stoma competition. All were so different that the editorial team found it hard to decide between them, so we are printing the best and asking you, our readers, to pick the winner.

Several readers have written to tell us that everyone assumes that people who have a colostomy must have had cancer. They feel there is little mention in the magazine of the other conditions which may lead to a stoma. We are attempting to redress the balance: in this issue we include articles written by ostomates whose stomas were formed because of incontinence and a bowel prolapse. They demonstrate that in these circumstances the concerns are slightly different. Our - I include myself here as my stoma was due to a long-standing bowel problem - stomas may not have been formed to save our life, but to improve the quality of our lives, to relieve pain or put an end to embarrassment.

I hope you enjoy this Spring edition of Tidings and I look forward to reading your letters and receiving your contributions for future issues.

Best wishes,

Rosemary

Rosemary Brierley
Editor

If you have a story, poem, article, letter or any other item you would like to appear in Tidings, please send them with any relevant photos or pictures to: The Editor, Colostomy Association, 15 Station Road, Reading Berkshire RG1 1LG or e-mail them to cass@colostomyassociation.org.uk We will do our best to include them.

Don’t forget to supply us with your name, address, phone number and e-mail address, if you have one.

Hints &Tips for

Skin Care

around your stoma

By Wendy Osborne
in conjunction with SALTS

Good skin care is a crucial part of any stoma care routine, because it will help maintain a healthy skin around your stoma and assist in successful stoma bag adhesion. If the skin becomes red, sore or broken this may increase the risk of leakages and further skin damage. Left unattended, the skin condition may worsen, leading not only to increased worry and discomfort for you, but difficulty in getting your appliance to stick, which may lead to the problem becoming worse.

There are many reasons why the skin around your stoma may become sore, so it is important to know what may be the possible causes, and know that you can do something to reduce the problem. The main reason is usually the output (faeces/poo) getting directly onto the skin or underneath the flange/pouch which should be protecting the skin immediately around your stoma. Infections, underlying skin diseases such as eczema and skin sensitivities to the products are less common reasons for skin problems.

I hope that by reading this article you will find some hints and tips which may help you to prevent or identify any reason for soreness, and will encourage you to contact your local Stoma Care Nurse to treat or review your stoma if you have any queries or concerns.

Wendy Osborne
Clinical Nurse Specialist – Stoma Care
Cheltenham General Hospital

Some of the reasons why soreness or leakages may happen...

Sore skin

There are many reasons why the skin around your stoma may become sore, so it is important to know what may be the possible causes, and know that you can do something to reduce the problem.

➳ Read on and Ask yourself...

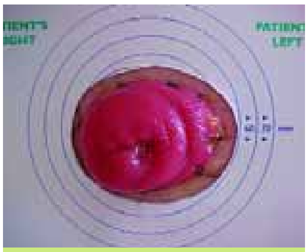
Has the shape or size of your stoma changed?

- Does your stoma look larger or smaller than it used to?
- Is there any skin showing around the stoma when you place the template over the stoma to check the size, or, is the size of the hole smaller than your stoma?

Suggestion...

Use a template (or the backing off your stoma pouch/flange) to check the size of the hole that is cut in your stoma pouch/flange – it should fit snugly around your stoma.

Checking your template:
If you are not sure how to do this, please contact your Stoma Care Nurse who can check your template for you.



Incorrect

Correct

Has your tummy shape changed?

- Have you put on weight or lost weight? This will change the shape of your tummy and may change the shape of your stoma.
- Have you got any skin creases, scars or swellings around your stoma (e.g. a hernia?) These will make the area around the stoma uneven and prevent the stoma pouch/flange from sitting flat against the skin.

Suggestion...

Once again use a template to check the size of your stoma as mentioned above.

If you have any skin creases etc., there are many seals and even different types of stoma pouches/flanges that can be used to help create a flat surface round the stoma.

Seek advice and a review by a Stoma Care Nurse who will be able to assess your stoma and the skin around it to help you find a solution to any changes.

Has the output from your stoma changed?

- Are you getting diarrhoea?
- Have you recently had any changes in your medication? (For example are you taking any antibiotics or having chemotherapy?)

Suggestion...

If the output from your stoma becomes loose/watery it has a greater chance of leading to a leak – fluid will find any weakness from which to escape.

Please contact a Stoma Care Nurse to discuss any such changes.

Do you have any lumps or bumps around your stoma?

- Have you noticed any bleeding from these lumps/bumps?

Suggestion...

Sometimes small lumps/bumps appear at the edge of your stoma. These may affect how your pouch/flange sticks around your stoma, but also they may be prone to bleeding. If they bleed this will make the back of your pouch/flange wet/blood stained and prevent it from sticking as well as it should do.

It is normal for the stoma to bleed a little as you are cleaning it (the bit of bowel that your stoma is made out of needs a good blood supply to keep it healthy).

If the bleeding is more than normal or you are getting problems with soreness or leakages, please contact your Stoma Care Nurse to check these lumps out for you.

Do you find that the faeces gets stuck at the top of the pouch/bag and does not drop down into the pouch?

This is called 'pancaking'. It happens as a result of the filter in your stoma pouch letting all of the air out and creating a 'vacuum effect' within the pouch. As the faeces builds up at the top of your stoma pouch, it can push itself under the adhesive (sticky part of your pouch) and cause skin soreness.

Please contact your Stoma Care Nurse to discuss this further.

Here are a few hints and tips to keep the skin around your stoma healthy

- Only use warm water when cleaning the skin around your stoma
  Soaps and baby wipes often contain perfume or moisturisers. These may affect how your pouch/flange sticks or may irritate your skin.

- Check the size of your stoma every few months
  Make sure the hole in your stoma pouch/flange fits snugly around your stoma. If it is too large, skin will show and be irritated by the stoma output, which can make it sore. If the hole size is too small, it may cause the stoma to swell.

- Take your time when changing your pouch
  Careful removal of the pouch will help to prevent any trauma/damage being caused to the skin. Always ensure that you check the skin around the stoma for any signs of early irritation and that the skin is dry before putting on your new pouch/flange as this will help the pouch to stick better.

- Gentleman, if you need to shave your skin around the stoma
  Avoid using shaving creams or hair removal creams as these may irritate the skin. We suggest you use clean warm water and a new disposable razor to shave the area.

- Accessory products
  There are many good products (wipes, creams and adhesive removers) that are available to help protect the skin around the stoma. Contact your Stoma Care Nurse or the Salts Healthcare Helpline for any advice or information on their use.

Remember: You don't have to put up with sore skin or leakages. If you are having problems, contact your Stoma Care Nurse to arrange a review.
Salts Healthcare Helpline, 0800 626388 or the Colostomy Association Helpline, 0800 328 4257, can give you the contact number of a local Stoma Care Nurse.

Skin integrity is essential for the normal usage of a stoma appliance and adaptation to life with a stoma depends largely on the health of the peristomal skin. For this reason, Salts Healthcare is delighted to be the first ostomy product manufacturer to be accredited by the British Skin Foundation for its research and development of comfortable, secure and skin friendly adhesives.

Ps. A few more...

To ensure the skin around your stoma is dry before applying a pouch, you can use a hairdryer, turned to the lowest setting.

Warm your clean pouch or flange on the radiator for a few minutes before putting it on. This will help the adhesive to stick to your skin.

When shaving the skin, hold the cardboard inside tube of a toilet roll around your stoma to protect it.

Update...

on new stoma care products and services

Five companies contacted us with details of stoma care appliances and services that have been introduced within the last three months

Coloplast have launched SenSura, a new generation of ostomy bags based on a revolutionary new technology. In clinical trials against other modern ostomy products (reported in British Journal of Nursing, 25 January 2007) eight out of ten users preferred SenSura.

The SenSura double layer adhesive effectively combines all crucial benefits that cannot be achieved in a single layer adhesive. The darker lower layer absorbs excess moisture to maintain a healthy skin condition. The lighter upper layer is extra erosion resistant protecting the skin and the lower layer from stomal effluent. With its oval shape and flex pattern SenSura is exceptionally flexible. SenSura ensures superior adhesion and is easy to remove.

The unique SenSura dual wave filter optimises all essential filter functions: air flow, deodorisation, leakage protection and active life of the filter. The improved hygienic Hide-away outlet on SenSura drainable can be folded up to reduce the bag to half its size for more discretion. Split soft cover bags featuring a transparent film underneath the soft cover facilitate application.

A complete SenSura one-piece drainable and closed bag range without convexity is now available. To obtain samples complete and return the coupon which appears with the company's advert on page 31. Products with light convexity will be made available later this year.

Salts Healthcare - These days everyone seems to be “surfing the web”. We use the internet for so many different reasons: to order our grocery shopping, to obtain bargains on sites such as Ebay, or purely to research information on a specific topic or task.

Now you can also order samples and your stoma supplies online. In fact, at Salts Medilink we have redesigned our online ordering site to make ordering your stoma supplies online even quicker and easier than before.

If you would like information about placing orders online, please call Salts Medilink on Freephone 0800 626388 and we will be pleased to answer your questions and ensure you are registered to use our ordering site. Alternatively, if you wish to order samples only, simply log onto www.salts.co.uk and click on ‘Samples’.

UCI Healthcare - All new customers who choose to use UCI Healthcare's personal prescription service will receive with their first order, a complimentary RADAR key to enable them to access over 6000 secure, clean, disabled toilets across the UK. In addition, they will receive the RADAR Directory which lists the locations of the toilets, with their third order.
For more information please call Freephone 0800 7314376.

In 2006 UCI Healthcare created a new division, Peak Medical, to act as exclusive distributors for the well established range of EuroTec one and two piece ostomy product ranges, which are manufactured in Holland. Their one-piece pouches are available in a variety of styles and pre-cut sizes. The new SuperSoft 2 piece flanges incorporate a very flexible hydrocolloid which is welded to a ‘closed cell’ foam layer making them one of the most flexible and comfortable flanges currently available on prescription. As well as a normal flat faceplate, there are also shallow and deep convex versions available for those with problematic stomas who wish to increase their product wear time. There is a good selection of closed pouches to use with the flanges. All of the Combimate two-piece flanges and pouches are interchangeable with Convatec's Natura range of products providing even more choice for ostomists. Should you wish to obtain samples please call Freephone 0800 652 0424

Fittleworth Medical Ltd, the home delivery service, have introduced a new Locker Box, which can be given to patients following operations to keep all their appliances, wipes and disposal bags close to hand. The box has an innovative silver based coating that is naturally resistant to a large range of bacteria including MRSA, Streptococcus and E.coli. The Locker Boxes are available free to all patients being discharged onto the Fittleworth Medical home delivery service. For further information call free on 0800 378846.

Fittleworth Medical Ltd has opened new offices following a recent expansion. They began trading in 1986, and until recently were based in the village of Ford. The unit at Ford continues to be used as a delivery depot and the 25 care centre staff have moved to the new offices in nearby Littlehampton. The new premises boast a state of the art customer care centre and a clinic room where stoma and continence clinics will be hosted.

Hollister are pleased to announce the launch of a new flange for two-piece users. The new Hollister Conform 2 with Adhesive Border adds to Hollister's range of two-piece products and is available in both standard and convex versions. This new product features Hollister's latest Flexwear hydrocolloid providing security and enhanced durability, with a unique non-allergenic adhesive border. This new adhesive border provides users with:

- Enhanced security – no more extra fixings required
- Extreme flexibility – moulds completely to your body shape
- Stretchable – moves with your body
- Lightness – lighter than all other two-piece systems

The Conform 2 with Adhesive Border are available in both cut to fit and pre cut sizes, and with connection ring sizes of 45mm/55mm/70mm.

Also available from Hollister are our new Hollister Adapt Barrier Rings. These rings are manufactured from a new formulation of hydrocolloid skin barrier, Flextend M. This unique formulation prevents barrier disintegration even when wet, and adheres well to your skin whilst maintaining your skin's condition.
With this latest barrier ring, you can bend, stretch or shape the barrier to provide a secure and comfortable fit and prevent possible leakage from around your stoma. The Hollister Adapt Barrier Rings are available in two sizes: 48mm Cat No. 7805 and 98mm Cat. No. 7806.

If you would like to try samples of either the Conform 2 with Adhesive Border or Adapt Barrier Rings, please call Hollister Patient Services Department on Freephone 0800 521377.

Information on new products and services received before 21st May 2007 will be considered for inclusion in the next issue of Tidings

Ray Goddard
Office Manager & Trustee
Colostomy Association

Out of Hours...
Telephone Helpline Service

At present the Colostomy Association has thirteen volunteers who man the helpline out of office hours: after 5pm in the evening and throughout the weekend. All these volunteers have successfully completed the Telephone Helpline Association training courses.

They all have a colostomy themselves therefore know what it's like to live with a stoma and are able to provide practical help, support and reassurance. However, the advice given is strictly non-medical.

If you call our Freephone 0800 328 4257 they will be happy to answer any queries or listen to your concerns.

Tuesday 6.35 pm...

The phone rings.

'Hello, Colostomy Association. Can I help you?'

For a few seconds there is silence.

'You're a real person. I was expecting an answer-phone.'

'When the office closes at five, the helpline volunteers take over. People like me who have a colostomy.'

'All I wanted was to ask for a travel certificate.'

'That's OK. I'll tell the office. You'll have it in a couple of days. Where is it you're going?'

'Greece... but I've not been on an aeroplane since I had my colostomy. I'm a bit worried...'

'So was I the first time, but not now...'

'Really...'

The call ends at 7.15pm.

Sunday 2.40pm...

'Is that the Colostomy Association?'

'Yes. How can I help?'

'Well... I'm having the operation next week. My stoma care nurse has told me all about it but she can't tell me what it feels like to have a bag.'

'I've had one for fifteen years.'

'And how d'you get on with it?'

'I hardly ever think about it any more, but it did take a bit of getting used to at first...'

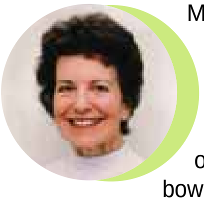
The call ends at 3.20pm.

F r e e p h o n e

Hello. I'm Gloria and I got my colostomy ten years ago in exchange for a cancerous tumour. It was a good swap, I think, because I live a very full life with my husband, daughters and granddaughters and enjoy it immensely. I retired from teaching three years ago when I was fifty-nine and enjoy reading, walking, crafting and my computer.

I'm Janice. I had my colostomy when I was thirty-three for colon cancer. I have a married son who has just made me a proud grandma. I was a proud Mum at my daughter's graduation. I work full time for an Insurance company and enjoy swimming, keeping fit and foreign holidays with my husband. You might have seen my photo in Tidings last year with Tom Cruise on my fiftieth birthday trip to London.

I'm Judith. I had my colostomy ten years ago because of rectal cancer. I was a French teacher for thirty years or so, and now, in semi-retirement, I still teach younger children as well as adults. In my spare time I'm learning Breton - far more like Welsh than French - as for the last three years we've had a house in Brittany, which I love - for the neighbours, the walking, the food and the peace!



My name is Pat. I had my colostomy in 1986 after many years and operations for bowel and bladder problems, since the birth of my son in 1959. Before having the colostomy, like most people, I thought it was the worst thing that could happen to me, but I was proved wrong as the quality of life improved 100%. I became a volunteer for the Association in 1988 and a Helpline volunteer in 2002.

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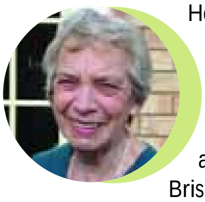
Hi, I'm Ernie. I had my Colostomy in 1995 just before my forty-fifth birthday after treatment and surgery for cancer. Now as an early-retired granddad my spare time is split between the Colostomy Association and as a volunteer with my busy stoma care team at the University Hospital. After almost ten years I still find my work at the hospital very rewarding and on average speak to fifteen or more patients each week.

My name is Marilyn. It is six and a half years since my colostomy was formed following complications with a peri-anal abscess. After several months of coming to terms with my altered plumbing I read an article in Tidings and subsequently became a volunteer for the, then, BCA. I am married with three grown-up children and four grandchildren and live on the beautiful Gower Peninsula. I'm very proud of being Welsh and, although I only have a smattering of the language, I can sing!

I'm Sue. In 1997 I was forty-six and leading a very busy working life in Germany, where my husband was in the army. I thought I had irritable bowel syndrome, but then I began passing blood and a colonoscopy showed a cancerous polyp, which had to be removed. Chemo and radiotherapy followed. I developed thrombosis, became very ill and was sent back to the UK. More surgery followed fifteen months later and 'Bertha' the bag was born! I haven't looked back since!

I'm Judy. I had my colostomy in 1996 for rectal cancer. Before and after my operation I worked in the NHS but am now retired and enjoying it. I love gardening, planning theatre trips and holidays. I was devastated when told I had to have a colostomy, but with the support of a dedicated stoma nurse and wonderful husband, soon got used to it. I enjoy being a volunteer for the Association and helping others to realise that there is life after a colostomy



Hello. My name is Iris and I have had a colostomy for two and a half years. I helped as a volunteer at the Bristol branch of an international helpline for a number of years. I am retired and have two very caring daughters and three grandchildren. I am a 'bit' person in my spare time: I do a bit of embroidery, a bit of tapestry, a lot of reading and knit some very strange looking garments. I have to admit I am a 'bit' nervous about travelling too far from my comfort zone.

Hi, my name is Maureen. Because of colon cancer I had a colostomy in 1979. There was no help with problems or appliances and this made me realise how important support is. I became involved in starting support groups in London and since moving to Norfolk have helped start another in King's Lynn. I come from a business background and with a husband in aviation have travelled quite extensively. I enjoy being on the helpline knowing that I, perhaps, can make a difference.

My name is Robin. I went to Dartmouth Naval College in 1940, joining HMS Jamaica, a cruiser covering Russian convoys, in 1943. I served in frigates, minesweepers, and survey vessels until 1959. Then I worked in greenhouses, also for Tesco, and as a leaf tobacco buyer and shipper. My colostomy was formed soon after I retired. I first 'helped on the phone' at the Eccleston Square office of the Colostomy Welfare Group in 1986.

My name is Rosemary. I had my colostomy in 1990, after years of bowel problems, which began with an abscess and ended with a rectal prolapse. Before my operation I worked in the NHS, but afterwards I took a job with the Open University instead. I am sixty now and retired and enjoy writing, looking after my grandchildren, gardening, interior decorating and holidays abroad.

My name is Jean. I had my colostomy for colorectal cancer twenty-one years ago, when I was forty-nine. I am married and have three children and four grandchildren. I was initially recruited to visit new colostomates in hospital by my local Stoma Care Nurse and was given training by the, then, B.C.A. I have now retired after twenty years as a teacher in middle schools. I still maintain my interest in young people as I am also a volunteer for Save the Children and speak on their activities to schools and adult organisations.

Jean also arranges our helpline duty rosters. Finding out when we are available and coming up with a schedule that suits everyone can be a complicated and time consuming task. Thanks, Jean . Ed .

Member of the Telephone Helplines Association
Quality & confidence for callers to helplines

We are a member of the Telephone Helplines Association, which works with helplines to achieve the highest quality response to all those seeking information, advice and help on health, social welfare or educational issues via the telephone or other interactive technology.

We are willing to receive calls from people who are having problems with their stoma or need to talk about issues concerning their colostomy at any time during the evening or over the weekend. However, we would appreciate if, apart from exceptional circumstances, these calls are made before 10pm in the evening. If possible could routine calls or those requesting literature be made during office hours.

Readers Replies....about Colostomy Irrigation

The last issue of Tidings included a feature on irrigation. Stoma care nurses explained that this is an alternative method of colostomy management which involves keeping the bowel clean by washing water through it every day or every other day. They discussed the advantages and disadvantages and explained why some patients are able to irrigate while others are not. Colostomates who irrigate wrote about their experiences.

We received a number of phone calls, e-mails, and letters in response to these articles. Here are some extracts with your opinions and comments.

I found the article on irrigation in issue No 4 of Tidings very interesting. The piece by Ernie Hulme about plugs was also very informative.

I had my surgery in 1988 - an AP resection for bowel cancer. Almost as soon as I was fit enough, my surgeon mentioned irrigation to me. In fact, he said that in his experience of working in the States the majority of colostomates irrigate. This was mentioned in the article. My Stoma nurse found me an excellent nurse who taught me how to go about it. After a few `false starts` I soon mastered the technique. I have used this method of bowel control ever since. I simply cannot imagine having to manage a pouch every day. To me it seems so much cleaner. I do realize, of course, that it isn't for everyone. It works for me and I am very grateful to my surgeon for his suggestion all those years ago.

The piece about plugs was of interest to me because, as soon as I was able to irrigate, I was told of the plug. I have used this method ever since with no major problems. I do have a prolapse and the plug does hold back the swelling to a moderate extent.

Best wishes.
W.H.

I greatly appreciated all your articles on irrigation as so little is talked about it and I was beginning to feel I was the only one who irrigated! I started twenty years ago, two months after my operation. It works really well for me even though we travel a fair amount and enjoy long distance walking, stopping overnight at different hotels and B&B's.

I agree with all the various points that your other readers make, especially about the savings of appliances and the cleanliness of waste etc. I find irrigating on alternate mornings before breakfast to be a relaxing experience and fairly quick (usually 30-40 minutes from start to finish).

The point I would like to add to other reader's comments is that the stoma nurse who showed me how to irrigate suggested that I sit on a chair next to the loo. This is what I always do so am very comfortable and able to read sitting back - far more easily than on the toilet seat. I have read many books in the 15-25 minutes on alternate days when I need to be seated at the toilet in this way!

Irrigation is well worth trying (the earlier after your op. the better) and persevering with, if a few problems arise. I can't remember the difficulties I had now - it is too long ago - but I recall that on some occasions I was tempted to give up. I am thankful that I persisted and I now have no problems.

Thank you again for your encouraging articles.
M.H.

Dear Editor

The very informative and useful articles in Tidings issue 4 was of particular interest to me, as I have been irrigating for over ten years.

You asked for feedback so here goes. I often feel that the people who make the appliances obviously do not have to use them. To start with, the reservoir you show in the magazine is probably the most sophisticated, but the most impractical. Have you ever had to hang it up and fill it with a jug? No, not very easy! And the flow indicator? Yes! A very good idea but too clever and bulky: a simple little bubble in a plastic ball in the flow line would be sufficient. There is a reservoir produced by another company which is excellent: easily hung up, very easy to fill, and I do not think it can be bettered.

Now the question of irrigation sleeves: the makers of this excellent reservoir make the most useless sleeve. The sleeve you have illustrated is a bit old fashioned and has never been improved in at least ten years. The top clip could be an all plastic sliding clip as they have on Zip seals. This could even be closed with one hand. Now the sleeves usually have to be cut to size, and the bottom I usually clip to the top with two clothes pegs. Now surely a small bar sliding clamp would be neater, easier to use and, most important, more comfortable.

I have suggested these improvements to two manufacturers. They say, "What a good idea". I think it is just lip service. Maybe they make a better profit from bags than from irrigation - or am I just a cynic? Maybe if they read this they might make some improvements to their products.

Yours sincerely,
D. G.

Taking the mystery out of irrigation...

Dear Editor,

I read with interest your articles on irrigation in the last Tidings magazine and, as I have been irrigating successfully for five years, I would like to add some useful advice.

It was mentioned that sitting on a toilet seat for any length of time was uncomfortable. I was taught from the start by my stoma nurse to sit on a chair facing the toilet with the sleeve going into the toilet, the water bag hanging up behind the toilet. It is a very comfortable way to irrigate and I cannot imagine sitting on a toilet seat for any longer than is necessary. Of course, room in the bathroom is essential, but for holidays I have a tripod folding stool to use if I find myself in cramped conditions.

One question in your 'Dear Nurse' section was about not being able to get water in after many years of success. I believe that it is down to relaxation, the more you are unsuccessful, the more tense you will become, so lots of relaxation I think is the order of the day!

I hope these tips are useful.

Kind regards,
M.W.

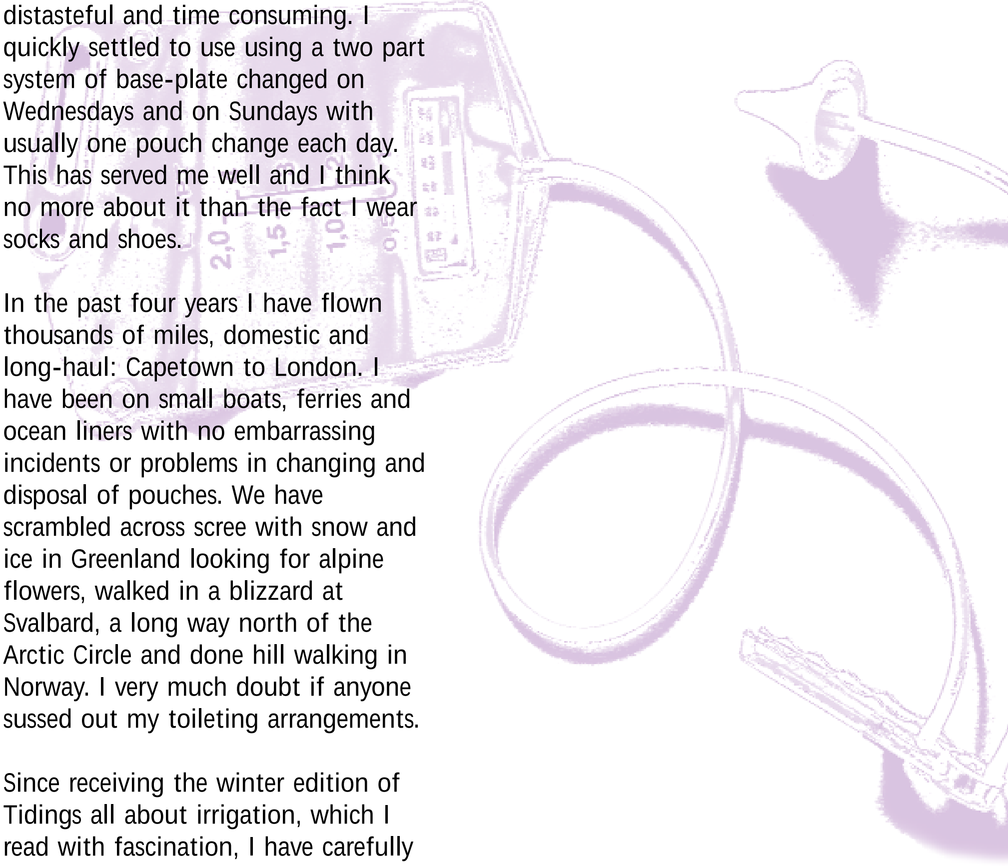
Dear Editor

Your latest issue of Tidings includes a number of very interesting articles and letters. I am pleased that all confirm that I am keeping pace with the market. I irrigate using a Braun pump, use toilet flushable pouches and also use the Conseal plug.

I accept that not all ostomates can use these methods for medical reasons. But what surprises me is that other ostomates still use products which are not friendly to the environment and often create cost. My colostomy operation for bowel cancer was during mid 2002 and I can remember in those early days looking for dog waste bins because I was embarrassed to use other disposal methods, especially away from home.

I will be seventy in July and attend a gym twice and swim once a week. I also eat and drink what I like. I am a member of the Mid Yorkshire Cancer Partnership Group and have attended a Macmillan Cancer Voices Workshop. There is at present a fairly active ostomy group which meets at Dewsbury Hospital every month.

Yours sincerely
D.N.



Dear Editor

I learned about irrigation soon after my operation about four years ago. It seemed to me then to be somewhat distasteful and time consuming. I quickly settled to use using a two part system of base-plate changed on Wednesdays and on Sundays with usually one pouch change each day. This has served me well and I think no more about it than the fact I wear socks and shoes.

In the past four years I have flown thousands of miles, domestic and long-haul: Capetown to London. I have been on small boats, ferries and ocean liners with no embarrassing incidents or problems in changing and disposal of pouches. We have scrambled across scree with snow and ice in Greenland looking for alpine flowers, walked in a blizzard at Svalbard, a long way north of the Arctic Circle and done hill walking in Norway. I very much doubt if anyone sussed out my toileting arrangements.

Since receiving the winter edition of Tidings all about irrigation, which I read with fascination, I have carefully timed my sanitation: 10am on Sunday before leaving home for church until 10am the following Sunday -17 minutes in total!

I was amazed to read about time spent in the bathroom and the lists of paraphernalia used. I do realize that having a stoma, as with anything else, means different things to different people. But anything from twenty minutes to forty minutes, admittedly every other day in some cases! Do they have Sky TV in their en-suite bathrooms, or dare I say it, do they like seeing their poo in liquid form! And lots of gubbins: irrigation sleeves, clips, toilet fluid... plus all that time.
No thanks
D.L.

Before considering irrigation, it is essential to check with your surgeon that this form of colostomy management is possible with your particular type of stoma and medical history. The technique needs to be taught, and the first attempts supervised, by a stoma care nurse.

Volunteer Profile...
Paul Foulger

Paul in 2003 when he started flying again following his "cancer journey"

In November 2000 Paul Foulger was diagnosed as having 'Squamous Cell Cancer – Poorly Defined'. Because the cancer was not affecting any organs it had obviously been growing for some considerable time, and was, initially, considered inoperable.

A subject no-one wants to talk about...

During the year 2000 I knew that there was something not quite right, but just couldn't decide what it was. I had suffered with my back, and visited an Osteopath on several occasions; he asked me whether the 'waterworks' were OK. They were. As far as I was aware I had no problems apart from 'piles'. This was only intermittent, but towards the end of October it was getting worse so I went to see my G.P.

I was prescribed suppositories, but there was no improvement so my G.P. referred me to a 'bum' specialist. After an initial chat about the symptoms, I had the inevitable examination of the back passage for the 'pile' problem. I was then asked, "What is this? There is a tumour in there! How long have you had that?" I was at a loss since I was completely unaware that there was anything amiss. It was obvious that all was not well and appointments for an Ultrasound and a CT scan were arranged.

When my wife, Penny, and I saw the 'bum' specialist again, we were told that whatever I had planned to do with my life would probably not happen. The prognosis was life threatening and my life would change radically, but he would refer me to another specialist who may be able to help. We left the clinic absolutely gobsmacked - we had well and truly been knocked into the ground.

Having slept on the news, we saw my G.P. the next morning; he was supportive and helped us to come to terms with the future in a more positive way. At this point I decided that I should resign as Chairman of Chelmsford College Corporation, as it was becoming clear that my health would take up my time and energy over the next few months.

The call to see the Colorectal Specialist came on 23rd November. I had yet another examination and, as he studied the CT scan, the specialist was quite careful to say that he was not, at this stage, entirely sure whether the tumour was benign or malignant, and he would need to get a better sample to find out. Two days later the Colorectal Specialist telephoned to say that the tumour was 'Squamous Cell Cancer – Poorly Defined'. He would refer me to an Oncologist, as I would need some form of treatment before surgery could be contemplated. On Wednesday 13th December, I was summoned to see the Oncologist, who questioned me closely about my medical history. I told him about the Hodgkin's disease I had suffered some forty years earlier. It appears - but no one can be categorical about it - that the weak radiotherapy treatment, I had some forty years ago, was probably partly the cause of the Squamous Cell Cancer I now had. This cancer is a form of skin cancer attached to tissue in the pelvic area, but it seemed that no organs were affected. I had not lost any weight, if anything I was putting it on.

In mid December a line was inserted into my arm so that it would be easier to administer the chemotherapy and five days later the treatment began. At the hospital I had four hours of saline, then an hour of Cisplatin, then a further four hours of saline. Cisplatin is chemotherapy that can have a number of side effects, particularly nausea and constipation, but there are plenty of tablets etc to counteract all this. After the last saline I had a 'Walkmed' fitted to feed in Fluorosil over 5 days. I went home the next morning, feeling reasonably well, particularly when everyone said that I would feel terrible with the 'chemo'!

One funny things sticks in my mind about Christmas Eve 2000. We always have the neighbours in for a drink but thought we had better not on this occasion so sent out a 'round robin'. I had no sooner delivered them and got back indoors when the phone rang. It was one of the neighbours who asked, “How long have you got?” What a question! It took me by surprise and for once I was lost for words! I think if I had been quicker I would have said, “A damn sight longer than you!” It just goes to show that people think of cancer as the end!

On January 1st a friend took me up for a flight in a glider to celebrate the New Year. My chemotherapy was to continue until March, running concurrently with radiotherapy which began at the end of January and involved going to Colchester five days a week for six weeks. During this time I became progressively more tired, but did manage to continue chairing the Gliding Club’s committee meetings and running my Pre Retirement courses.

Then on Thursday, 29th March, I saw the Colorectal Specialist again. He was pleased with the progress of the chemo and radiotherapy, and said that there was now the chance to operate. He said I would most definitely need to have an irreversible colostomy, and there was every chance that he would have to remove the prostate and bladder, which would mean a urostomy as well. The former I had always been aware of. However, the second one was news to me and knocked me sideways. I contacted the Colostomy and Urostomy Associations who sent me lots of useful material, and helped me to come to terms with some changes in the future daily routine of my life.

I was given a date for surgery – 21st May. I was admitted two days before and allowed just “free fluids” – soup and jelly for lunch and supper and plenty of water. Also I had to take a delightful tablet called “Picolax”, excellent for purging the system! To add to the problem, there were two of us being purged, and the ‘loo’ paper ran out! Luckily for us some was found.

Following the journey to the operating theatre, the epidural was put in my back. The next thing I remember is seeing Penny on the ward after the op. I then slept until about 6.00 a.m. the following morning. At last the operation was over, and by 7.00 a.m. I was sitting in the chair next to my bed, and continued this all day. I had no pain, and, considering the operation took some five hours and involved handling my guts, I was really quite surprised.

I seemed to have a constant flow of visitors, although on the Saturday, five days after the op, I had a bit of a down day. I had been warned that this was a possibility - I still had to come to terms with the stoma. Initially the stench was almost unbearable. However, as each day passed, it got better. On the Monday the specialist said that in a couple of days I could go home, provided the stoma nurse was happy that I could cope. Before I left he told me the good news - results from the pathology lab showed the cancer was all removed.

Once at home the District nurse called everyday for a couple of months to ensure the wounds were clean. The tummy wound was thirty-two staples long and did weep a little, but wasn’t a problem. However, the wound at the rear took longer to heal since this is where the radiotherapy took place. When the stoma nurse visited me four weeks post op, I told her that I had got a bag change down to eight minutes and she was pleased with my progress. She came back to see me the following week to explain irrigation and I realised I would not be bound to wear a stoma bag every day. Instead I could do what many non-ostomates pay pounds for - colonic irrigation.

In the eleventh week after my surgery the stoma nurse visited me three times to start me off on the irrigation regime. It worked very well, but having to wash out the drainage bag on each occasion I found quite repulsive. I now have a supply of drainage bags for single use, which is much more acceptable. The following week I took another step forward and ordered some stoma caps - a sure sign that the use of stoma bags, day in and day out was coming to an end.

Three weeks later the District Nurse came for the last time as the perineal wound was almost healed. I felt this was a good sign as I was progressing towards complete independence again. The following Saturday, Penny and I flew to Portugal for a cruise on the River Duoro. Each day the boat sailed inland, and we’d go on the coach to visit various places, and to my surprise I managed all the trips. Although I was tired I wasn’t over tired and therefore felt the benefit of the holiday. We met up with a very nice couple on the boat, and it transpired that the wife had had a very similar experience to me. It was good to be able to talk to someone who had also been through hell and back. We both agreed that it is essential to talk about the cancer. It helps to get one through the bad times as well as let others know what is going on.

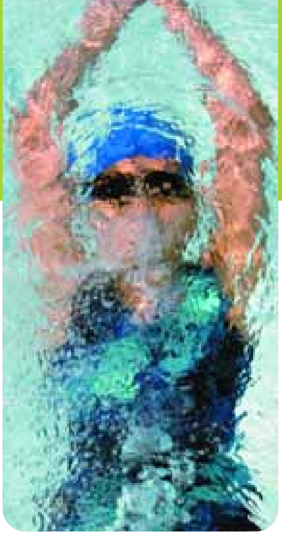
Although I was back organising my Retirement Courses six weeks after surgery, I still had a lot of discomfort in the perineal area, due to an infection, which required treatment with antibiotics. I developed an abscess which, at twenty-one weeks post op, burst and reopened the perineal wound. However, I am glad to say that the wound healed in record time.

Six months after the operation, irrigation has become second nature. It only needs to be done every two days and I have full control over my stoma. I even manage to irrigate when we go to stay in the caravan. The only problem that I have now is that my stoma has herniated. When I spoke to the surgeon about this he told me that this is very common among ostomates so it looks as though I am going to have to live with it. A small price to pay for life.

Extracts from a diary Paul Foulger kept from November 2000 when he was first diagnosed until November 2001, six months after his operation.

Now, six years later, Paul is working as a consultant in catering and pre retirement education as well as being a member of the Cancer Peer Review Team and a volunteer for the Colostomy Association.

What to Wear?



The replies we received to our questionnaire showed that many readers would like our magazine to include a feature on clothing for ostomates.

Many of us who have stomas are able to find suitable clothing in ordinary retail outlets and High Street stores: Marks & Spencer's underwear range includes a full brief with a low leg-line and light support garments. Swimwear in a patterned fabric or a design, which is ever so slightly gathered or ruched across the tummy is very effective in disguising any bulges. Tankinis are an ostomate's answer to the bikini.

However, other ostomates may prefer underwear or swimwear designed specifically for ostomates. A specially designed inside pocket may provide extra reassurance especially if the output from the stoma is very fluid. A little support may help those of us, without a hernia, who do not require a specialist support garment.

We have therefore asked three manufacturers of clothing for ostomates to tell us about the products they produce...

White Rose Collection

If you have trouble finding underwear and swimwear to suit you on the high street then we will be able to help...

We have a wide range of underwear and swimwear for both ladies and men.

Feeling secure and comfortable begins with having the correct underwear and our high-waisted designs are designed specifically for people with stomas. Each design has a full-width, inner pouch which will easily accommodate all types of stoma bag. This provides extra comfort and support, stopping the bag from dropping down the legline so you can wear the same styles that you would have done before your operation. Swimwear also has the same type of pouch and a double lining at the front which, combined with the fabric designs, means that you can be confident that your bag will not show when swimming, even when wet.

The underwear covers all age groups and includes everyday basics to luxury, handmade, silk designs. We also have sportswear designs, loose cami sets and pyjamas; several of the designs have matching tops. New products this year include a modern microfibre range, bodies and some designs specifically made for intimacy. Swimwear covers everything from skirted suits to tankinis, bikinis and swimsuits for both holiday/beach wear and serious swimming.

The men's catalogue contains high-waisted trousers and shorts, underwear and swimwear. It can be a problem to find comfortable clothing, particularly if the stoma is situated on the waistline. Our designs help to overcome this.

WHITE ROSE COLLECTION

JUST MEN

"Products for people with Stomas, from people with stomas"

Comfort, Confidence, Security

Ladies Range
A wide range of underwear for lady ostomates from basic everyday wear (includes full length bodies) to luxury silk. All our briefs have a special inner pouch to keep your bag secure and out of sight.

Extensive New Swimwear Range
A selection of swimwear styles with our inner pouch and double lined fronts for confidence and security. Ideal for swimming, aqua aerobics and beachwear.
Popular range of two piece designs available

'Just Men' Range
We have a good selection of higher waisted trousers and shorts, including summer trousers.
Also swimshorts and underwear with higher waist and special inner pouch for comfort and security.

Designed by an Ostomate
We know what having a stoma is about so you can talk to us in complete confidence and we will understand your issues and needs. Our products have been tested and used by ostomates over the last four years and are recommended by stoma departments. You can order from us in complete confidence as we offer a full money back guarantee

Please ask for our free mail order catalogue

White Rose Collection Ltd . PO Box 5121 . Wimborne . BH21 7WG . England
Email: info@WhiteRoseCollection.com . tel: 01202 854634 .
Visit our website at www.whiterosecollection.com

The company was started in 2002 by Tanya Hutton who had an ileostomy at the age of thirty. When she found that high street underwear and swimwear was not quite suitable for her, she set out, with husband Dave, to design and manufacture their own range. Being a fellow ostomate she had a good idea of what was needed. New designs have been added over the years following customer feedback.

Whenever you call us you will be speaking to someone who understands your situation and can discuss requirements in complete confidence. Full mail order catalogue available. Call 01202 854634 or visit www.whiterosecollection.com. You can also meet us at exhibitions countrywide.

new

LADIES SWIMWEAR FEATURES

A discreet security pouch
A full front lining
Soft cups
Scooped back

AVAILABLE IN SIZE 10 - 24

MENS SWIMSHORTS FEATURE

High Waist
Draw string tie for added security
Inner pocket with Velcro fastening
Close fitting inner stretch pant

AVAILABLE IN SIZE Small - 2XL

Order our NEW brochure TODAY! Call us on
0800 220300

OstoMART
Swimwear

OstoMART Ltd

OstoMART manufactures a range of clothing designed with ostomates in mind. Our range includes casual trousers, underwear and swimwear. Each collection is skilfully crafted from high quality fabrics and manufactured within the UK at our own factory. Whilst we offer a wide range of sizes, we are also able to offer a bespoke service if required.

Our entire range of ostomy underwear features extra length in the body from crotch to waist. This ensures that the waistband doesn’t cut across the stoma and pouch, (unlike most High Street brands), thus providing the wearer with both comfort and confidence. Our styles include Y Front & Boxer for the men and cotton maxi briefs and light control briefs for the ladies. Cumfie stretch pants are classed as unisex and are made from a super stretch, fine mesh material. They are ideal for dressing support whilst remaining virtually undetectable under normal clothing.

Casual trousers are available in either a fleece back jersey or in a “Denim Look” Cotton/Polyester/Lycra mix fabric. The denim look is especially popular with ladies as they are extremely lightweight and comfortable, whilst remaining very smart.
Each pair of trousers features our signature high waist for added comfort, has leg vents and invisible zips at the front. The fleece back jersey option has a back flap pocket.

A choice of sizes and leg lengths are available (please state when ordering)

The men’s swimwear range is available in a boxer style. These feature a high waist which is fully elasticated, plus an added draw-string for extra security. Inside each swim short is a close fitting stretch pant, ideal for discretion and confidence when wearing a pouch. Fabric choices include plain or pattern designs.

Our ladies swimwear collection offers a fabulous range of one and two piece designs.

We have a choice of six patterned fabrics with co-ordinating plain fabric for the two piece range, with the added choice of short style pant or high leg pant. (Please state preference when ordering) Whichever style is chosen, you will find the garment has soft cups, has a discreet inner security pouch and is double lined. The one piece styles have an added feature of ruching on a central angled seam, this allows greater discretion whilst wearing a pouch and the gathering can be on either side, depending on which side the stoma is sited. (Please state which side is required when ordering.)

February 2007 marked the launch of a brand new on line shopping experience from OstoMart. You can now purchase all of our products from the comfort of your own home using the OstoMart Store Internet shop. www.ostomartstore.co.uk If you prefer traditional shopping, call us on 0800220300 and we will be happy to send you a full colour brochure.

What to Wear?

CUI Wear

Offer beautiful and functional underwear purpose-made for both women and men...

Our underwear is purpose-made in the latest modern designs and fabrics – from luxury satin and silk to soft pure cotton and supple microfibre, trimmed with fine Italian lace or Swiss cotton.

The expertise this company brings will make you feel comfortable, confident and secure with all your underwear requirements. The stoma garments have been extensively tested and developed in the UK with the help of stoma nurses and their patients.

The range is designed to enable the wearer to experience a sense of great comfort and confidence as the appliance is supported and held securely. The system eliminates the risk of the pouch slipping out and, for drainable pouches, it also eliminates the clip/tab rubbing directly onto the skin.

Fulcionel is a modern range of hernia support garments. This range is made from the latest fabrics that offer exceptional support and comfort. The garments can be supplied plain fronted or, if advised by your nurse, a hole can be cut for the pouch. The range offers a variety of styles and colours for ladies and men.

FREEPHONE -

0800 279 2050

www.cuiwear.com

Ladies and Mens HIGH waisted underwear with patented in pocket to support your ostomy pouch.

AVAILABLE ON PRESCRIPTION

Ladies Jacquard Brief

Sizes 8 - 24

Ladies Jacquard Shortie

Mens Boxer Shorts (loose fit)

Sizes Small - XXLarge

Mens Fitted Cotton Lycra Trunks

These items are available on prescription through your GP.

For more information and a prescription request form, Please contact CUIWEAR FREE on

0800 279 2050

www.cuiwear.com

Specialist Hernia Support Underwear

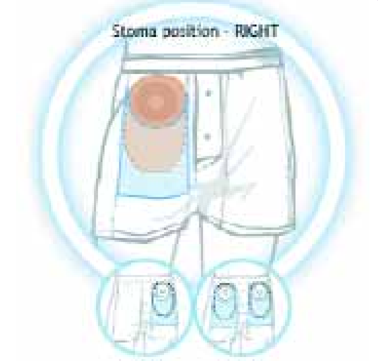
- Hernia Support
- Hole cutting facility
- Prompt availability

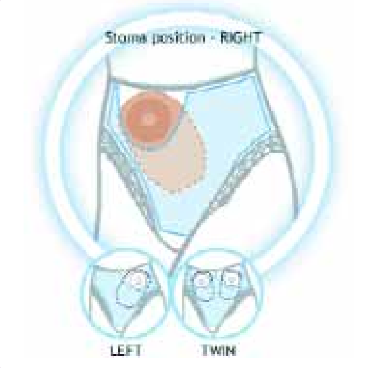
Mens with & without legs

Various Ladies Styles

The proprietary support system is unobtrusive and conceals the appliance within the underwear.

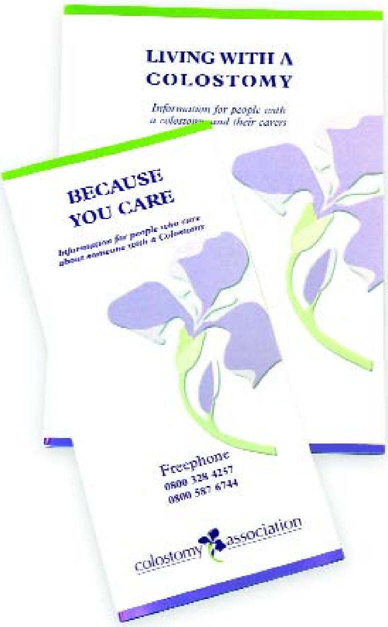
“The range is designed to enable the wearer to experience a sense of great comfort and confidence as the appliance is supported and held securely.”





CUI produce a large range of underwear and swimwear. A catalogue is available and can be ordered on line at www.cuiwear.com, by calling Free phone 0800 279 2050 or by writing to CUI Wear Ltd, Freepost NAT3363, Leicester LE8 4BZ.

Focus on the Colostomy Association Head Office...



As the Managing Trustee of the Colostomy Association I have the responsibility for running the Head Office in Reading and am ably assisted by Gill Herbert (Administrator), Jo McKenzie (Database administrator), Beryl Goddard (Helpline and Support Group administrator) and two of our volunteers Jackie Dudley and Monty Taylor. Beryl, Jackie and Monty are colostomates and have a wealth of knowledge between them.

No two days are ever the same in the office but we strive to ensure that we provide a professional service to our members, nurses, manufacturers and suppliers. The office is open from 9.00 a.m. until 5.00 p.m. Monday to Friday and we deal with a wide range of queries which we receive via the telephone, e-mail and post. On an average day we can receive between 15 and 20 telephone calls – this inevitably increases after each Tidings magazine is despatched and can be as high as 35, so we apologise if you cannot always get through to us around this time. We aim to respond to all incoming requests within twenty four hours and this does sometimes include undertaking our own research to answer any specific questions raised.

As the associations Head Office we are frequently the first point of contact for many enquiries and it is important that we provide responses in a swift efficient manner. If necessary, we will always approach one of our highly valued volunteers for advice or to make contact with somebody on our behalf. We are also heavily involved in the supply of information to our members and helpline callers. We have a wide range of booklets and leaflets covering many aspects of living with a colostomy. Some of these have been compiled with the assistance of our volunteers whilst others have been supplied by the manufacturing / supply companies. We are also working towards including a lot of this information on our website.

We obviously deal with a lot of business administration for the association such as paying bills, expenses to our volunteers, banking etc, as well as maintaining the details of all of our members on our database. We work closely with manufacturers and supply companies and assist them when they are planning patient information days and open days. This usually involves labelling envelopes to go out to members who live in the area of the meeting and arranging for one of our volunteers to attend.

For callers to our Helpline we maintain a list of our volunteers who are willing to talk to other colostomates about specific topics. We also maintain a database of nurses and provide them with our information leaflets and copies of the Tidings magazine. We recently sent out a questionnaire to over 500 nurses to find out how aware of the association they were and how we could assist them more. We had a very good response to this questionnaire and are currently analysing the results.

Fundraising is something that we are very passionate about at Head Office and we explore all opportunities that could benefit us. This could range from talking to companies about advertising in Tidings, to researching the legalities of running a lottery scheme or looking at having our own branded Christmas Cards for 2007.

Another very important part of the work that we do at Head Office is to act as the voice of the colostomate. We are very aware of the many issues that could impact on our members and we are very involved in reviewing the Department of Health proposals for changes in the provision of Stoma Care Appliances. Along with representatives from other patient support associations, I have attended a number of meetings over the last six months to discuss these proposals and details of these can be found in a separate article in this issue. We have also raised specific issues with the British Airports Authority to explain the need for colostomates to be able to carry their spare appliances in their hand luggage, the B.B.C. to express our distaste of how colostomates were being portrayed by a comedian and a manufacturer about the withdrawal of products.

Last, but not least, we are part of the editorial team producing Tidings each quarter. This takes us right the way through from planning the magazine, gathering contents, liaising with advertisers and contributors, proof reading, working with Art Direct on the design of the magazine, arranging the printing and finally liaising with the mail house to ensure that the magazine is despatched on time.

As I mentioned at the start of this article, no two days are ever the same in the office but, hopefully, the above gives you an insight into how we spend our time ensuring that we provide the services that you need from us.

Ray Goddard
Managing Trustee

colostomy association

Update on the Department of Health Consultation

Many of you will know that in 2005 the Department of Health (DH) put forward plans to reduce spending in providing certain services. As part of this they proposed a 15% reduction in the costs of supplying stoma products.

Since then there have been a number of consultations and we, the Colostomy Association, have been involved as part of PIPs in reviewing the mountains of paperwork produced.

So what is PIPs? This is an acronym for Patients Industry Professionals Forum. It is a partnership of people from the nursing profession, the healthcare industry and patient groups (like the Colostomy Association).

The aims of PIPs are:

- to safeguard standards of patient care and promote best practice trading.
- to provide a Forum for debate to improve patient care and services.
- to make representation to government on relevant issues.
- to make and deal with responses to consultation documents.

The aims of patient groups are well known to their members. The nursing groups make obvious participants of PIPs. But you may not be familiar with the organisation which represents the healthcare industry on PIPs. This is The British Healthcare Trades Association (BHTA). It hosts and works at the centre of PIPs.

The BHTA was founded in 1917 and is now the oldest and largest healthcare trades association. Today it represents about 350 companies and over 17000 people who work in the member companies. These companies are both large and small, and may be involved with manufacturing products (like stoma pouches) or providing services (like delivery services).

But back to the DH and their consultations. The first brought over two thousand responses from many quarters. As a result a number of the proposals were abandoned and further consultations planned. Two further consultations followed.

> “Rest assured that the Colostomy Association will continue to be at the forefront of any consultations which will impact on our members. We will go on fighting to ensure there is no reduction in the quality or quantity of products and care that you now receive.”

One of these was specific to the provision of dressings and chemical reagents. That brought only 63 responses, and the other was concerned with provision of stoma and incontinence appliances and related services to patients (51 responses were received). Very few changes were made to the proposals outlined in these consultations and this may well be down to the low numbers of responses.

By the time that you read this article the final date for responses to the latest two consultations will have passed and we will have submitted our views on the proposals.

These latest consultations are aimed at how stoma product manufacturers will be paid for the products and services that they provide. Our concern is that the consequences for patients could be wide ranging. The current proposals could result in some products becoming uneconomical to produce. They may mean that funding for nurses will be reduced.

Many of you have already been contacted by your suppliers asking you to outline the impact that the proposals could have on you if they go ahead and if there is a reduction in the range of products provided.

You may well have responded to the consultations yourselves through the Department of Health website and I can assure you all that the patient groups have ensured that their responses have linked back to the key main aim of the whole process. This aim was stated, by the DH, to be “To maintain and, where applicable, improve the current quality of care to patients”.

Once again, the DH may well be surprised by the number of responses they have received. Rest assured that the Colostomy Association will continue to be at the forefront of any consultations which will impact on our members. We will go on fighting to ensure there is no reduction in the quality or quantity of products and care that you now receive.

So the PIPs Forum with its mix of professional nursing bodies, patient organisations and the BHTA is significant in the DH consultation process. PIPs has worked extremely hard to safeguard the interests of patients as well as the healthcare industry as a whole. The work continues, but we must all realise that a government department determined to cut costs is like a juggernaut that can’t be stopped, only be slowed down!

Scottish Executive – National Review Group

The Colostomy Association is also represented on the National Review Group in Scotland. This is the body involved in reviewing the success of the changes which were implemented there in 2006.

The National Review Group meets every couple of months to review and discuss specific issues. It is made up of a combination of NHS representatives, Patient Groups, Appliance Suppliers and the Scottish Executive Health Department.

If any of our Scottish members have had any problems since the changes took place please feel free to contact us and we will raise the issue on your behalf at the next Group meeting.

Ka'anapali Beach, May 2006
Stella and Nick get married on Maui, an island in Hawaii. With them, in his traditional Hawaiian costume, is Rev. Kimo Kirkman, the minister who conducted the wedding ceremony.

Starting Again...

A colostomy was not the must-have designer accessory that I had in mind when, at the age of thirty-six, an infection following a routine operation destroyed my bowel muscles. I spent two weeks in intensive care with peritonitis, pneumonia and septicaemia and a further five months in hospital. Then I tottered home. After a year of faecal incontinence it was decided that a colostomy was my only option. By this stage I really didn't care; ANYTHING would be preferable!

My colostomy and I got to know each other and I learnt swiftly that it was never to be relied on, except to let me down when I least expected it. Wilful, with a mind of its own, we had to get along despite me cherishing the idea that if I ran very fast I could leave 'it' behind. There were bad days, lots of them, and embarrassing occasions when all I could do was to cry, but the quality of life it gave me was good. I could enjoy my two small children, go out with them, go on holiday, do all the things I had done before I had my operation. Life was 'normal'.

Sadly my marriage failed, and in 2000 I was divorced and moved away. After a couple of years 'on my own' although loving my independence I was lonely and I missed having a special person. The prospect of dating again in my late forties with 'Ming the Merciless' (my name for my stoma, from the baddy in Flash Gordon) was daunting. I like fashionable and attractive clothes and hope that my colostomy is never evident (friends have assured me of this). A lot of it is 'in the mind'. You feel that the whole world can see this 'thing' underneath your clothing, but believe me they can't! After a couple of years of going out and meeting men (some of them lovely, some of them...not so lovely), I met and fell in love with the man who I married earlier this year - on a beach in Hawaii.

> "There were bad days, lots of them, and embarrassing occasions when all I could do was to cry, but the quality of life it gave me was good. I could enjoy my two small children, go out with them, go on holiday, do all the things I had done before I had my operation. Life was 'normal'."

When I realised the relationship was becoming serious I had to tell him about 'Ming the Merciless' to give him the option of heading off into the sunset. I felt that if he really loved me he would cope with my extra companion. He was wonderful and said that as he loved me, Ming was part of me and therefore it was no problem. I still had concerns about the first time he saw me without my clothes...his comment was 'Is that it? Is that all?' I could have wept with relief.

We had a fairy tale wedding on the beach and life is pretty good...So, all of you out there worrying about starting again, go for it! We've all been given a second chance at life since having a stoma.
So seize the moment firmly and enjoy!

Stella O'Keeffe

An Ostomate's Guide to Holidays and Travel

If you've had your colostomy for some time you probably won't think twice about going away on holiday, but for the new ostomate the prospect of travelling for the first time after surgery can be quite daunting.

These are some of the questions we receive on the helpline...

- How will I cope with my colostomy on the aeroplane?
- Can I take my spare supplies in my hand luggage?
- I'm having trouble getting insurance. Can you help?
- How will I manage if I get a tummy upset?
- How will I get rid of used pouches when I'm staying in a hotel?
- Is it OK to go swimming?

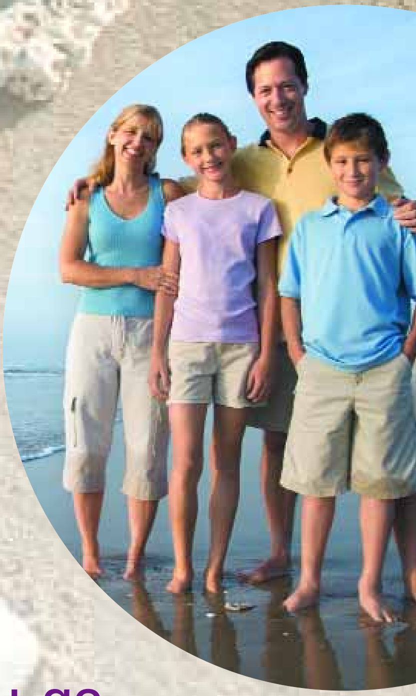
In the following pages we attempt to provide some of the answers...

One of our volunteers, a seasoned traveller, brings us up to date on airport baggage regulations and shares tips about travelling by air.

A colostomate who works in the insurance industry explains how having a stoma can affect the premiums, but it pays to shop around. He emphasises the need to declare pre-existing conditions and the importance of reading the small print. He also discusses what is and is not covered by the EHIC card.

There's an article on retiring to Spain and details of an adventure holiday for 6 to 18 year olds.

Also hints and tips for travellers...



So read on...then pack your "bags" and off you go...

Ostomates Abroad...

Monty in Tiananmen Square
May 2006

Monty Taylor is our new volunteer at Head Office. Since his colostomy operation four years ago he has travelled extensively: flying to Australia & New Zealand, China, Sri Lanka and South Africa. We asked Monty to pass on some tips about travelling abroad. He has also researched the current situation regarding airline regulations about carrying ostomy equipment and found out which delivery companies are willing to send supplies abroad.

Ostomates travelling abroad can enjoy their holiday as much as their companions provided, before departure, they make additional preparations for their comfort both whilst travelling and at their destination. Department of Transport regulations now limit all airline passengers leaving UK, irrespective of travelling class, to one carry-on bag measuring 56x45x25cm (22x18x10in) and not exceeding 5-7kg in weight.

Before departure:

1. Order adequate supplies for your holiday in good time, making sure that you have sufficient additional equipment in cases of excessive need (tummy upsets etc.). It is recommended that you take at least 50% more than you think you will need.

2. Get a travel certificate from the Colostomy Association but also ask your GP for a letter explaining your condition and the necessity for the supplies you need to be in your hand luggage (Some GP's make a charge for writing this letter).

3. British Airports Authority (BAA) are now fully aware of the problems of ostomates needing supplies to be taken on board personally and the Aviation Security Department at the airport from which you are travelling should now have been advised. Contact them in good time before your departure date to seek a dispensation but if you still encounter problems after approaching them, speak to The Colostomy Association Head Office and they will put you in touch with someone at BAA security who should be able to help.

4. Alternatively you can pack as much as possible within the limits of your permitted bag, and perhaps persuade your travelling companions to take some supplies for you as well. Remember that "airside" you can purchase reading material etc. for your journey and therefore use your carry-on capacity before security check-in for essentials only.

5. If you are travelling with an airline having on-line check-in, use it and if possible choose your seat rather than take pot-luck at the check-in desk.

6. If your stoma is in an "awkward position" get a protector so that your pouch will not be trapped by the safety belt – if you are on a long journey and there is turbulence you might be strapped in for quite a long time!

7. If two of you are travelling together ALWAYS divide your clothes between your suitcases in case one should be lost and do the same, if you are restricted on carry–on baggage, with your colostomy supplies.

8. Make sure you have adequate travel insurance to cover any excess costs incurred in obtaining emergency replacement supplies.

9. Scan your passport, visas, driving licence (card and paper sections), insurance policy and tickets and store them in your email address as, if you lose them, there is an electronic version available online anywhere in the world for you to print out and use in an emergency.

Day of departure and the flight:

1. Some people, worried about changing their bag during the journey, will have eaten very little the day before travelling. However, it is best to eat normally, but perhaps smaller portions and avoid foods like beans and high fibre foods as they can cause wind. Choose your time to use the aircraft toilet - passengers seem to head for them either just before or immediately after meals so don't get stuck in the queue! Although airline toilets are relatively small, everything is easily to hand and should not present a problem.

2. If you are taking a long flight, make up a small selection of your supplies in a wash-bag/make-up bag so that they are readily accessible from your hand luggage for you to take to the toilet. In case of an "accident" a change of clothes (or at least underwear) and a large plastic bag can be very useful.

3. Try and wear loose fitting clothes for a long journey as cabin pressurisation can cause swelling of feet, ankles and sometimes around your waistline but rarely results in your bag ballooning. Before boarding the aircraft just check that your bag is empty and comfortable. Drink plenty of water and get up and walk around when you are able to do so.

Luggage missing on arrival:

1. If you are travelling with a tour, advise your tour rep immediately. Explain the problem, hand them the small bar code baggage tags (usually stuck to your boarding pass or passport) and ask that they immediately instigate a trace with the airline to establish the whereabouts of your bag. If travelling independently go directly to the airline desk at the airport. Make sure you get a “lost baggage” form from the airline with the necessary information to make a claim on your insurance.

2. If, as a result of the lost/delayed bag, you are going to have a problem over supplies you will need to make contact with the supplier where you are staying who will have the necessary equipment. Remember that you will have to pay for the replacements (I was recently quoted 85 Euros for a pack of 30 bags in Marbella). Keep all your receipts as they will form part of your travel insurance claim when you return home.

Long trips abroad:

1. If you intend to spend a long period abroad it is important for you to check before you leave the UK as to the availability of supplies in the countries you propose to visit.

2. We have spoken to several suppliers to establish their policy for sending supplies abroad (see table below) but check with your own supplier before leaving UK as they may not necessarily deliver to the country you are visiting.

3. You may find it more convenient and cost effective to arrange for repeat prescriptions from your GP to be collected by a friend or relative and supplies obtained by them. The parcel should state clearly on the outside: “Urgent Medical Supplies” and be sent by courier.

4. Remember, if you do have goods sent to you abroad, that Custom’s Duty might be charged before you can collect the parcel.

5. Be aware that the USA make exhaustive enquiries about goods before release - a supplier reported that one package took six weeks.

It is quite surprising how many countries in the world have supplies, but of course you will usually have to pay for them. I was in Shanghai recently and saw a shop selling hospital equipment with a sign above the window saying “colostomy supplies”. Whilst preparing this article I did a web search and this firm came up so this could be an alternative way of finding a supply albeit not necessarily a manufacturer you usually use. If all else fails you could always call at the main hospital where you are staying; if they do not have supplies themselves they may know where to obtain them for you,

Monty Taylor

Delivery companies willing to send stoma supplies abroad

Supplier	Policy
Braun Medical 0800 163007	Will send to an address abroad. No postage or delivery charge will be made.
Clinimed 0800 585125	Will send abroad but have had problems with import charges levied by Customs. Officers check packages at random.
Charter Healthcare 0800 132787	If going abroad for more than two months will send supplies.
Dansac 0800 581117	Dansac are a global company and supplies should be available abroad. Contact UK office to find out if the country to which you are travelling will have the product you need.
Fittleworth 0800 378846	Will send anywhere abroad free of charge on receipt of prescription.
Pelican 0800 747400	Will send abroad at no charge.
RapidCare 0800 181901	Will send anywhere in the world. No charge for despatch and always mark the packages “Medical Supplies”.
Salts 0800 626388	Will send abroad without charge and cover the cost of any Customs Duty.
Trent Direct 0800 0284131	Will send anywhere abroad, but if it is a long way would share mailing costs.

NB: Details correct at time of print

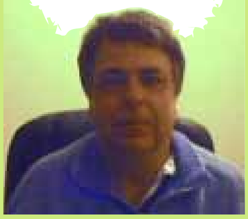
Don’t forget your Travel Certificate...

This handy wallet-sized booklet can be obtained by ringing the Colostomy Association helpline on 0800 328 4257. Fill it in with your details then get it countersigned by your doctor. Keep it with your passport and in your hand when going through security checking. It explains that you have had a surgical operation which makes it necessary to wear a medical appliance and you will be carrying medical supplies in your hand luggage. If there is need for an airport search, then a qualified medical practitioner must be present.

Two travel certificates are available with the information translated into different languages:

1. French, German, Italian, Spanish, Portuguese, Greek, Turkish, Croatian, Polish & Russian.
2. Thai, Vietnamese, Arabic, Hindi & Mandarin.

Travel Insurance...Points to consider



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

Peter Martin is a Senior Account Executive for a large insurance broker in the Bournemouth area. He is also a colostomate and has been a volunteer for the British Colostomy Association and now the CA for over twelve years. We asked Peter for his advice about obtaining travel insurance, particularly for those of us who have a stoma. We also asked him to answer some of the questions we are frequently asked on the helpline.

To obtain a European Health Insurance Card (EHIC) fill in an application form obtainable from your local post office or apply on line at www.dh.gov.uk/travellers or call the EHIC Application line on 0845 606 2030.

Remember that an EHIC card will not necessarily cover all the costs of your treatment and never covers the costs of getting you back home in the event of illness or accident.

For more information on the countries where it is valid and the medical treatment it covers see the booklet Health Advice for Travellers.

As usual the weekend newspapers and magazines have been full of articles and adverts trying to entice us away on holidays to all parts of the World. Not surprising when the Association of British Travel Agents (ABTA) says that about 45 million trips abroad are made from the UK every year. This is the time most of us start making plans and researching potential destinations.

Part of these plans should include the consideration and purchase of travel insurance. Price is often the main criteria in selecting a policy with little or no consideration being given to the covers and limits provided. This is very dangerous as no two travel insurances are the same and, in the case of colostomates, the way potential insurers consider pre-existing health conditions is of paramount importance.

Travel policies are offered normally for a single trip or on an annual basis. They can be arranged to cover the UK including the Isle of Man only, Europe including the Channel Islands only, on a worldwide basis or worldwide excluding the USA/Canada and the Caribbean. Costs vary according to the area travelled in, the period of travel, the cover provided and the age of the traveller. Up to the age of seventy, there are many insurers but the market, as you get older, sees the numbers of insurers reduce considerably. Premium rates increase and the facility of an annual policy is in many cases withdrawn altogether.

The provision of medical emergency and asscociated expenses cover is very important, with a limit of £5 million being fairly standard. This may need increasing if you are going to travel to Canada, USA, or the Caribbean, where the cost of medical treatment is very expensive and many people seek a limit of £10 million.

All travel policies contain a pre-existing health condition and include a declaration in respect of the health for each person insured. If you cannot agree with all the statements contained in the declaration, you will need to contact the insurer's health line. Trained personnel who have a medical background will treat your information in the strictest confidence and assess whether or not a particular condition or conditions can be included. If cover is accepted you will be given a reference number and some insurers may require a premium loading and/or an increase in the policy excess (the first part of any claim you have to pay). An additional £50 added to the excess is fairly standard.

Some insurers are reducing the length of the declaration by asking specific questions about named conditions and ailments, i.e. about the important illnesses that will affect the premium.

A declaration may be along these lines and, as far as I know, the following apply:

- Nobody is waiting for an operation, hospital consultation (other than regular check ups) or other hospital treatment or investigations.
- Nobody has received treatment, other than regular medication in the last twelve months for any form of cancer, leukaemia or tumour.
- Nobody has been seen by a specialist in the last three months (other than for regular check-ups) or been admitted to a hospital overnight.
- Nobody has been given a terminal prognosis by a registered doctor.

If you can agree the declaration for yourself and each person insured, you will not need to refer to the insurer and no cover restrictions will apply. For an annual multi-trip cover, you must agree with the health declaration each time you book a trip, and if circumstances have changed you must tell the insurer. It is also worth pointing out that insurers will not pay out for a close relative or business associate or anyone else who is not insured and whose health may affect the trip.

On the other hand, if you are still undergoing treatment such as chemotherapy or radiotherapy or have had recent surgery, the condition is unlikely to be covered. In any event insurers treat each case on its individual merits.

In such circumstances you should consider

either arranging a holiday in the UK and Isle of Man only or visit those countries where the European Health Insurance Card (EHIC) operates. The EHIC was introduced on 1st January 2006 and is a convenient plastic credit card sized replacement for the old E111 form. The EHIC entitles you to free or reduced cost state-provided medical treatment if you have an accident or are taken ill while visiting any country in the European Economic Area (EEA) or Switzerland. The EHIC also covers any treatment you need for a chronic disease or pre-existing illness and is normally valid for three to five years.

The EHIC is free to all UK residents and each individual traveller needs their own card. A list of countries where the EHIC is valid is contained in the NHS booklet “Health Advice for Travellers” which comes with the EHIC application pack. This booklet also sets out the treatment and costs involved for each country in the EEA and Switzerland. There are other countries with reciprocal healthcare agreements with the UK, notably Australia, Barbados, New Zealand and Russia. A full list is set out in the booklet.

Apart from pre-existing medical conditions, which cause a lot of problems, simple things such as riding quad bikes and jet skis, or mountain bikes or going horse riding are often not covered. You may fancy one of those banana boat rides where you are towed behind a speed boat; this needs to be checked with your insurer when you take out the policy, to see if it falls within their excluded dangerous activities. Activities such as winter sports can normally be covered for an additional premium and there are insurers who will consider the inclusion of extreme sports like bungee jumping, kite surfing and sea kayaking. If you are in doubt as to whether or not an activity is covered, you must check it out with the insurer.

You should check under what circumstances your insurer will pay out if you cancel a trip. Also find out about any excesses which is the amount you have to pay towards any claim - typically the first £50 or £100. There may be restrictions on claims, such as single item limits on baggage cover. Baggage/personal possessions cover is usually relatively low at £1500, with a single item limit of £300 - items such as sunglasses, mobile phones, contact lenses and golf clubs may be excluded. Household contents insurance policies may offer higher sums insured and higher single article limits under a personal all risks possessions extension that applies to items taken outside your home and is often done on a worldwide basis. In any event you should check that you are not paying for the same cover twice. Insurers will usually offer a discount of 10% to 30% if you delete such cover from your travel insurance.

Where travel insurance is offered free on credit cards or bank accounts, this can be misleading, ill explained or can lull the insured into a false sense of security about what is and what is not covered. It may be that the first person named on the account must be travelling with the party or the whole holiday needs to be booked with the card for the holiday to be covered.

Finally, you should make sure you have a 24 hour claims and 24 hour worldwide emergency services line to contact if disaster strikes. If you feel you need help with the options and covers available, you can always seek the advice of an independent insurance intermediary.

In conclusion, holidaymakers should not rush in and sign up for cover as soon as they find a cheap deal. It is vital to check that the policy on offer provides the cover you really need.

Peter answers the questions we are often asked on the helpline...

Q: Will having a stoma affect my insurance quote or is it just the cause of the stoma?
A: The stoma is not the problem because this is, in fact, a solution to the problem. If the cause has been eradicated or is under control, then insurance is normally available.

Q: How does the points system work?
A: To aid their assessment of the risk, many insurers adopt a points system. This takes into account the age of person, the condition being reported, how long they have had the condition, the date of operation (if applicable), details of ongoing treatment and medication, any future treatment and any other medical conditions. The cost of insurance cover will also depend on holiday destination, period of travel, whether the policy is for a single trip or annual cover.

Q: I've just had a colostomy operation following bowel cancer. What medical exclusions apply?
A: The cause, cancer, would be excluded by most insurers, usually for the first year but this will depend on any continuing treatment.

Q: I finished my treatment 6 months ago but still struggle to get travel insurance. Why is this?
A: Most insurers are aware that the chances of a recurrence of the original condition and potential side effects or complications following an operation or treatment are more likely during the first year.

Q: What is meant by ongoing treatment? Does this include the wearing of a colostomy bag?
A: The wearing of a bag should not fall within an insurer’s definition of ongoing treatment. But this can vary between insurers and should be discussed with the insurer prior to effecting cover.

Q: Does an outpatient appointment in the future constitute ongoing treatment?
A: This is unlikely, providing it is for a routine check-up. It is best to check with your insurer.

Q: I had my colostomy fourteen years ago and have a colonoscopy every five years. Is this ongoing treatment?
A: No, this is a precautionary screening process. However, if advised of a problem following this procedure you would then have to disclose this to any would-be insurer.

Q: If my luggage is lost can I get the cost of sending supplies out to me covered by my travel insurance?
A: The answer is yes, but bear in mind that the policy excess will apply.

Going on Holiday...get yourself covered

It is crucial to let your insurance company know of any pre-existing medical conditions. We have heard of instances where an ostomate failed to inform the insurer of their ostomy. When it came to claiming for a completely separate ailment, the claim was deemed invalid and rejected on the grounds of non-disclosure.

Here is our list of companies that we know will provide travel insurance for ostomates. We strongly recommend that you obtain quotes from at least four.

Please let us know about other companies that have treated you well and covered your medical needs, by writing to us at Head Office, phoning 0118 9391537, or by e-mail cass@colostomyassociation.org.uk.

Age Concern Insurance
Tel: 0845 601 2234
www.ace.org.uk/AgeConcern/
No limit on age. Will insure pre-existing medical conditions and cancer.

All Clear Travel Insurance
Tel: 0870 777 9339
www.allcleartravel.co.uk
Designed for travellers with disabilities or pre-existing medical conditions.

Chartwell Insurance
Tel: 0800 6524652
http://www.chartwellinsurance.co.uk
Covers medical conditions but you will need to answer a questionnaire. Offers cover for up to age 79 for a single trip, age 64 for annual cover.

Churchill Insurance
Tel: 0800 085 2436
www.uk.churchill.com
Only available on line.

Direct Travel Insurance
Tel: 01903 812345
www.direct-travel.co.uk
Senior citizen policy for age 66-79.

FlexiCover Direct
Tel: 0870 990 9292
www.flexicover.com
Age limit is 85.

Free Spirit (Pulse)
Tel: 0845 230 5000
www.pulse-insurance.co.uk
Insurance for travellers with pre existing medical conditions.
(only single trips for cancer conditions - not annual worldwide)

Go Travel
Tel: 0870 421 1521
Tel: 0870 112 6122
(Not obtainable on-line)
Their Blue Swan Policy covers medical conditions.

Insure and Go
Tel: 0870 901 3674
www.insureandgo.com
Medical condition must be over 5years ago to obtain cover.

J.D. (Consultants)
Tel: 01689 856984
Tel: 01689 851145
Tel: 01689 859102
Up to the age of 80. Covers pre-existing conditions and cancer.

MIA (Medical Information Anywhere)
Tel: 01268 782745
Europe only at present.

Marrs Insurance
Tel: 0870 920 2222
www.marrs.co.uk
Will cover pre-existing conditions

MediCover Travel Insurance
Tel: 0870 735 3600
www.medi-cover.co.uk
Single trips only. No age limit.
Will cover pre-existing conditions.
Medical screening required.

Post Office.
Tel: 0870 443 9721
Case by case screening and may incur additional premium.

RAC Insurance
Tel: 0800 55 00 55
www.rac.co.uk/insurance
Will cover medical conditions providing you have not been in hospital for that illness within last 12 months.

Saga
Tel: 0800 559 3231
www.saga.co.uk
No age limit. Pre-existing conditions covered. Cancer cover will depend on type of cancer and holiday destination.

Sainsburys Travel Insurance
Tel: 0845 300 3190
www.Sainsburysbank.co.uk
Screening required for all medical conditions including cancer.
Age limit 80.

Tesco Insurance
Tel: 0845 300 8800
Will offer cover with medical questions

VentureSure Travel Insurance
Tel: 0800 181532
www.venturesure.com
No age limit on single trip. (Sister company to Free Spirit)

Worldwide Travel
Tel: 0870 112 8100
www.worldwideinsure.com
Will quote if condition is stable and under control. Age limit is 74

Updated March 2007

Dear Editor

My first foreign holiday, after my colostomy operation on Friday 13th August 2004, was in June 2006. I booked a holiday to Bulgaria through “Going Places Travel Agency”. Although I was not covered for any complications to do with my bowel or operation, I did not have to pay any extra premium.

When I booked this year’s holiday to Italy, also through “Going Places”, although I reassured their insurance section over the phone that the tumour was fully removed and I did not take any medication - I no longer had cancer, but a colostomy bag - an additional £42 would be payable for me on top of the £25 each for a weeks holiday.

Taking the advice of the agent dealing with our booking I declined the offer. Next door was a Nationwide Building Society so I picked up a brochure. Their response to my answers to the same questions was that there would be no extra charge for my “condition” which would be fully covered at the slightly cheaper price of £49.13 for both the wife and I.

So do shop around for travel insurance as some companies are more understanding than others.

Yours sincerely
G.H.

Going on Holiday...

hints and tips

Just in case...

If you use a closed appliance, before you go on holiday it is worth telephoning your supplier and asking them to send samples of a drainable version of the bag you normally use. You can take these with you, just in case you suffer from diarrhoea while away. It is often easier to deal with loose motions using a drainable bag and it avoids the need to change the bag too frequently which can lead to sore skin. It is a good idea to practise using a drainable bag before you leave to get used to the method of emptying and re-sealing.

Sachets of Oral Rehydration Salts e.g Dioralyte, Electrolade etc. when mixed with water will replace fluid lost due to diarrhoea and prevent dehydration. So it is a good idea to pack some of these – especially if you are going to a hot country..

Coping with a colostomy bag while away from home...

There is no need for anyone to know that you have a stoma and it is perfectly acceptable to wrap your used appliance up well and put it in the pedal bin in the bathroom. Staff should empty these bins daily and handle and dispose of the contents hygienically as other guests discard babies' nappies and sanitary products in this way.
Some ostomates prefer to cut the bottom (or the top which is cleaner) off their used bags and empty the contents into the toilet before disposing of them.

It may be worth considering a toilet-flushable bag, where the soiled inner lining can be flushed away leaving only the clean outer bag to throw in the bin. However, do try them out before going on holiday in case you have problems and check with the manufacturer that they are compatible with the "drains" of the country you are visiting. We have heard of problems with this type of appliance in Greece.

Changing your bag when "out and about"

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

And remember a RADAR key will give you access to all toilets for the disabled in the UK, where there's always a wash basin and a bin to dispose of used appliances. See back cover of Tidings for details of how to obtain one.

Tips for colostomates who irrigate

In most Western European countries it's OK for most people to drink tap-water these days, but colostomates and especially those who irrigate need to be extra-careful. It's best to irrigate with only bottled water, making sure the seal on the bottle is intact before it's opened. Extra precautions when travelling further afield, where water supplies may not be so reliable, are water sterilization tablets, bought over the counter in the chemist's before you leave or a travelling kettle (with necessary travel adaptor), in order to boil the water overnight before use (warmed again if needed) the next day.

Make sure you have some means of hanging up your water reservoir. You can bend a wire coat-hanger into an S-shape to hook over the shower-rail. In case the shower isn't close to the toilet, take with you a supply of vacuum hooks (a suction cap fitted with a hook) which you can stick to a smooth surface like a mirror or tiles. However, be aware that these hooks cannot be relied on for prolonged periods as they may slide down the wall, so it is best to be safe and use two.

What about swimming?

Colostomy pouches these days are discrete and cannot be detected beneath a swimsuit, especially if it is patterned. However, if you are concerned about this, most manufacturers make mini-bags, so it is worth contacting them to see if they make a smaller version of the one you are currently using. Stoma caps cannot be seen beneath the skimpiest of swimwear.

In cool conditions the workings of our insides tends to slow down. As we all know when we first put our toe in the water, the sea and swimming pools aren't that hot, so there's unlikely to be any output from your stoma while you're swimming.

Food entering the stomach stimulates the colon into action, so it is best to go swimming before rather than after a meal.

If the filter on your stoma bag gets wet, this can cause it to become blocked later on. To keep it dry cover it with one of the sticky patches, now provided in all boxes of appliances, before getting into the water.

Young Colostomates...

a date for your diary!

Children and teenagers are often overlooked when it comes to living with a stoma. Many young people feel unable to talk to their peers and can feel very alone at times...but all this is about to change!

BREAKAWAY!

Break Away Weekend 17-19th August 2007

- The UK's First Family Activity weekend £120pp including a free t-shirt
- Bringing together young people living with bowel bladder diversions and their families
- REAL Adventure Activities – AALA license; qualified and experienced instructors
- Supported by the Ileostomy, Colostomy, Urostomy Associations and the NACC
- Funding Available
- Cost includes all meals & activities

Breakaway is the first ever UK adventure weekend, specifically for kids with stomas and their families. The weekend is designed for young people between the ages of six and eighteen with bowel or bladder dysfuntions. The weekend has been devised and organized by people with a full knowledge of living with bowel or bladder problems. This is a unique opportunity to meet families in a similar situation, to talk and share experiences and to take part in confidence building, action, adventure activities. In the USA they have annual camps for children with stomas, which are very successful, so hopefully this will be the first of many in this country.

The 'Breakaway Weekend' is to be held on 17th-19th August 2007. The chosen venue for this event is yet to be confirmed.

Want to know more...log onto
www.breakaway-visits.co.uk
or contact: 0775 1560013

Details about the weekend...

- A weekend of adventure, activities, fun and support.
- Activities may include archery, high ropes, canoeing, climbing, hill walking and mountain biking.
- Accommodation in comfortable rooms including many en-suites.
- Dietary requirements catered for.
- Support and advice from stoma nurses during the weekend.
- Funding support.
- All accommodation, meals and activities for only £130 per person, including exclusive Breakaway Weekend T-Shirt.

Moving to Spain...the right way

Cynthia Robinson, Expatriate Ostomates of Spain (EOS)

The sun is shining and the sky is blue as I look over the bay towards Ibiza. Here in the Valencian Region we are fortunate to have so many good things as well as the sweet oranges!

Soon the EOS Helpline will ring: perhaps it will be someone in a faraway place in Spain calling after having had an ostomy operation, perhaps still in shock from the diagnosis of their illness and from being told that they must live with a stoma, perhaps it will be someone in UK who wants to come to live here. We support them as well as we can, whatever and wherever the problem!

As ostomates, we need to have peace of mind - especially when travelling overseas. Spain has regional governments which can and do make their own laws. The information given here is basic. There are certainly variations to the procedures mentioned and these can and do vary from town to town as well as from region to region. For this reason alone it is essential for newcomers to have professional help as they work through the initial maze.

Who is covered by the Spanish health system?

- Those (including family members) who are contributing, or have paid contributions, into the system.
- Foreigners who are part of the health system of their home country if that country has an agreement with Spain- as do all countries in the EU - but to an extent that depends on their status as residents or visitors.

How can I obtain my ostomy supplies in Spain?

There is no manufacturing of ostomy supplies in Spain: all are imported by one of the five companies and there is only their limited selection of what is available in UK. Some items are still not available on the Spanish health system prescriptions and these include the wipes, disposal bags, deodorants, and much of the skin care which you may be used to receiving.

If you use a Home Delivery Service in UK, then ask them if they have a holiday service to Spain. If so, this can be used for a few months to cover the transition period (while you are still technically a visitor) and until you have your Spanish health card and doctor.
There are two levels of health services here - one for tourists and one for residents. The quality of care is the same, but the entitlement differs.

Tourists do not have a Residency Card, they do not work in Spain and they do not normally register with the local health centre. They may or may not own property in Spain. To have any entitlement to health services they need to bring with them the EHIC plastic card (which replaced the E111 in January 2006). Should there be sudden illness or accident, state medical treatment will be provided either free or at a reduced cost on production of this card, but it may not cover everything you would expect free of charge on the NHS. Operations or treatment for illnesses contracted before travelling are not covered. Remember that this card does not replace travel insurance and does not cover repatriation such as by air ambulance, which is a very expensive item should disaster occur.

Whilst on long holidays, tourists should sign on the 'Padron' (the list of persons residing in the town) at the local town hall, for which they receive a certificate. Then, if there is a problem, they can visit the local health centre emergency department with the EHIC, their passport and the important 'Padron' certificate to prove their right to be helped.

Residents are people who not only take up residence here but who have a liability to Spanish taxation generally (apart from non-residents who spend more than 183 days per year here and thereby fall into the tax net also). To be regarded as resident, one can occupy rented or purchased accommodation and in either case one must have an NIE (Foreigners' Identification Number) which is obtained from the nearest Hacienda (Inland Revenue Office). Once obtained, this number is needed frequently in Spain and is the equivalent of the Spanish citizens' identity card.

To obtain the plastic health card (called the SIP card) and be allocated to a doctor, you will need your 'Padron' certificate, the NIE, and your passport.

Unless exempt because they have been contributing to the Spanish Social Security as workers, pensioners were required to hold a 'Residencia' card. This indicates that the person is receiving an adequate pension or has other means of support. To apply for the Residencia card, you must obtain an E121 **before** leaving the UK. However, in March this year a Royal Edict was issued in Spain concerning the abolition of the Residencia. It is expected that this will gradually come into effect, but it could take time for every town hall throughout the country to have the new procedures and paperwork in place. Therefore, as of now, it would be up to the expatriate either to cooperate with officaldom or to insist that the card is no longer required, and perhaps be prepared to wait.

If you choose to stay in Spain, your initial tourist or visitor status will inevitably have to change to residency. Some people try to avoid this but ultimately it is at their own cost. Ostomy supplies are very expensive. When your UK doctor deletes your name from his list - as sooner or later he must - or the regular trips home to pick up supplies becomes a real pain, then you will need what the Spanish system has to offer. It is important to do as much research as possible before leaving home, because your health cover in your retirement will be vital to your peace of mind.

At the Expatriate Ostomates of Spain office, our Helpline often rings with questions covered in this article and we aim to help any ostomate who contacts us. As Expatriates in Spain we are in a minority and as ostomates we are a minority of that minority! We understand the problems because we have been there, and now, having done our best to follow the legal ways, we can have peace of mind to enjoy the lovely sunshine and even smile at Spanish bureaucracy!

Helpful Information:

For further information about re-locating to Spain contact: The Colostomy Association for the full leaflet “Moving to Spain-the right way”

Expatriate Ostomates of Spain
Telephone and HELPLINE:
+34 96 646 0063
Fax: +34 96 646 1563
E-mail: OSTEXT@euphony.es
Mailing address: Apartado de Correos 336, 03730 Jávea (Alicante), Spain
Web: www.ostomyinspain.org

Age Concern
Freephone 0800 00 99 66
www.ageconcern.org.uk for their Information Sheet: Retiring Abroad – What to consider if you are planning to leave the UK.

Diarrhoea
Your Questions Answered...

We frequently receive Helpline calls from colostomates concerned about a fluid and frequent output from their stoma. This may be ongoing or just a temporary problem.

Colorectal & Stoma Care Nurse Specialists:
Shelley Biddles RGN RMN Stoma Care 216
Di Wilson RGN RM Stoma Care216
answer your questions about why this happens and the best way to deal with it.

Changes of bowel function resulting in diarrhoea or constipation are common in the normal population. Normal function is not simply going to the toilet once a day; in fact normal variation is considered to be between three times a day and three times a week. For a colostomate there is no difference - these alterations in bowel function can still occur.

What causes loose motions or diarrhoea?

There are many reasons why you might suffer from diarrhoea.

- If you have had a substantial portion of your small or large bowel removed, loose motions will often be a consequence. One of the main functions of the large bowel, or colon, is to remove water from our waste and to re-absorb it into the body. Therefore a reduction in length, due to surgery, will create a faster transit time, in turn reducing the amount of water that can be reabsorbed.

- Some medication can cause diarrhoea, so do check with your doctor.

- Having a colostomy does not exclude you from suffering from gastro-enteritis. If your gut does not like a food-stuff, it will attempt to get rid of it as quickly as possible. In such cases, diarrhoea is normally acute and short lived and the best response is to give your gut a break from eating, but remember to drink water to prevent dehydration.

- Certain types of foods such as spicy foods can cause looseness and we mustn't forget what excessive alcohol can do!

- Modern living can be very stressful and our gut is a great reflector of our emotions - just think back to when you had exam nerves or when you went for that important interview.

Are there any tablets I can take?

Providing there are no contraindications, because of any underlying disease or any medication that you already use, you may take an anti-diarrhoeal, for example loperamide, to slow down the movement of the bowel.
However, be wary of anti-diarrhoeal medication which also have other effects i.e. codeine phosphate is a strong painkiller as well.

Have you any suggestions for coping with a very liquid output from my stoma?

It is easier to cope if you use a drainable rather than a closed stoma appliance. There are now several solidifying gels or capsules available on prescription. You can put these into your pouch and they will help to transform the liquid output into a thick paste.

My bag sometimes fills up very quickly and leaks. Is there anything I can do to prevent this from happening?

Again it is worth trying anti-diarrhoeal medication, and checking your eating habits. For extra security, flange extensions are available, but be cautious as these will not prevent the initial leakage under the flange. It may give you vital minutes, allowing you time to go and change your appliance. However, if left longer, the leak onto your peristomal skin has the potential of causing soreness, even excoriation.

I am worried about my bag leaking at night, particularly when I am away from home.

- Ensure your pouch is changed or emptied before retiring to bed.

- If there is evidence that your filter has stopped working properly, change your pouch.

- Don't have a heavy meal in the evening (after 6pm).

- Don't drink too much alcohol.

- Gel sachets or capsules can be used to solidify your motion.

If the above don't alleviate your worries, you can use a pad, similar to ones used in hospital, for protecting the bed. These can be purchased from your chemist and cost approximately £5 for seven.

I'm going abroad on holiday are there any precautions I can take so I don't get a stomach upset?

- Use bottled water – clean your teeth using bottled water as well.

- Be cautious of local delicacies.

- Don't eat salads that you haven't prepared yourself (using bottled water).

- Don't have ice cubes in drinks unless bottled water has been used.

- Avoid local ice creams.

- Take extra pouches as most people over-indulge to some extent whilst on holiday.

- Take some drainable pouches just in case required.

- Take a supply of anti-diarrhoeal medication. (Check with your GP if that is OK.)

- Make sure you have good travel insurance-just in case you need medical treatment whilst abroad.

Where diarrhoea is a chronic complaint in conjunction with other symptoms, such as pain or bleeding, then medical advice must be sought as an underlying medical condition may be the cause.

Information

What you want to know...

About CT or CAT Scans & MRI (Magnetic Resonance Imaging)

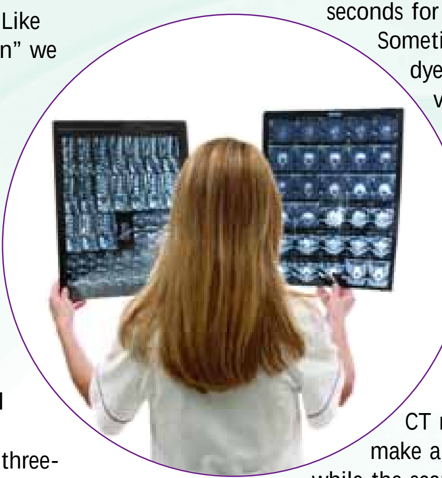
CT or CAT Scans

Many of you will have heard about having a CT scan. When this is first mentioned to you, how is it explained? Like anything that is "unknown" we worry about what is to happen.

CAT (computerised axial tomography) scans are far more detailed than ordinary x-rays. It is a method of body imaging in which a thin X-ray beam rotates around the patient. The information from the two-dimensional computer images can be reconstructed to produce three-dimensional images by modern CT scanners. They can be used to produce virtual images that will show a surgeon what he would see during an operation.

If you are to have a CT scan you may be asked not to eat for six hours before the test. When you arrive at the hospital you will be seated in the special area reserved for patients who are to have their scans. The nurse will come along with a jug of flavoured drink. This is quite pleasant (nothing to worry about – just a sweet liquid) and you will be asked to keep drinking until she is satisfied that you have absorbed enough. You are allowed to go to the toilet – as the liquid actually adds colour to the organs and so does not have to be retained in the bladder. You do not have to undress until the nurse is ready to take the scan. In a private room, you will be asked to remove your clothes and put on a hospital robe.

Once in the X-ray room, you lie on the bed and the scan begins – the scanner looks like a huge doughnut. The bed slides slowly backwards and forwards into the "ring" of the scanner. This allows the scanner to take a series of cross sectional pictures of the body. You may be asked by the radiographer to keep very still, hold your breath or avoid swallowing for a few seconds for each image.



Sometimes, a liquid X-ray dye is injected into the veins of the arm during the test. This makes it easier to see organs etc. There is a feeling of warmth in the arm, but this quickly passes.

CT machines usually make a whirring noise while the scan is being done and if you are nervous about this, ear plugs can be provided. A CT scan is painless and it usually takes about half an hour to perform, so it can be uncomfortable lying on a hard surface for this length of time. Once the examination is over, most people can resume their normal activities immediately.

MRI (Magnetic Resonance Imaging)

The magnetic field produced by an MRI scanner allows radio receivers (placed close to the body) to detect tiny signals from inside the body. A computer turns these tiny signals into two or three dimensional pictures.

An MRI scan is usually performed in a hospital as a day case. In many cases no preparation is needed. However, if you are having an abdominal scan you may be given special instructions in advance about eating and drinking. You could be advised to wear clothing that does not have metal parts: zips, under-wired bras etc., but in most instances you will be asked to change into a hospital gown. You will then be taken into a room which houses the MRI scanner, which looks like a large "box" with a hole like a "tube" through the centre.

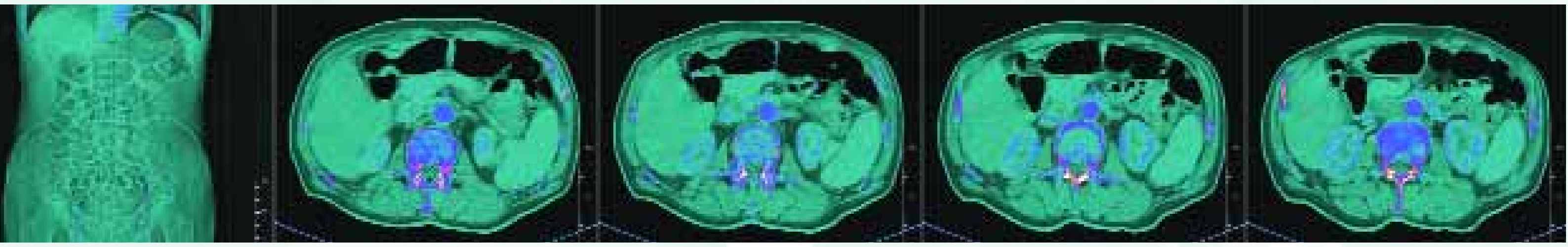
Sometimes a dye may be used to make some tissues show up more clearly. If needed, you will have the dye at the beginning, or sometimes towards the end of the scan. It is usually given as an injection in your hand or arm.

The scan itself can take from fifteen minutes to an hour to perform. The procedure is painless and does not usually require an anaesthetic. However it can be uncomfortable lying still for this length of time, so you may be offered a sedative that will help you relax.

You will lie on a table which will slide inside the large "tube". It can take several minutes for each picture to be taken and it is important to lie quietly during the process. The machine will make (very) loud noises (rather like a pneumatic drill) and you will be given ear phones through which you can listen to music. You can always take a CD of your own. When the scan is complete the table will be moved out from the scanner.

Your body will be encased in this "tube" while the imaging takes place – so if you do suffer from claustrophobia or are worried you must discuss this, beforehand, with the radiologist or doctor who will be present. Once the examination is over, most people can resume their normal activities but if you have had a sedative you will need to arrange for someone to drive you home.

Jackie Dudley



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*British Journal of Nursing, 26 January 2007

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"Name Your Stoma"- Help us to decide on the Winners

We received over eighty entries to the "Name your Stoma" competition telling us the apt and amusing names you call your colostomy.

The editorial team found it difficult to agree on a winner. So we are handing the decision over to you, our readers. We are also doubling the prize money.

As promised in the last issue we are awarding a £25.00 M&S voucher for the name you like best.

There will also be another £25.00 voucher for the letter that explains why a nickname, which at first sight seems inappropriate for a stoma, fits the bill so well.

We have short-listed eight names and are printing five letters for you to judge.

But first let's look at the entries...

Some names cropped up more than once. The most common was Winnie, as in Winnie the Poo(h). Several other readers called their colostomy Thomas or Tomas, which as several of you pointed out is an anagram of stoma, and as one person said is "a friendly name for something that at times can be rather unfriendly". There was Lou, "my ever friendly portable loo always with me" and Lulu.

Because it lives in a pouch, there were two Joeys and several Skippys - Do you remember the theme tune of "Skippy, Skippy the bush kangaroo"? Other television personalities included Mr Blobby and Hot Lips - remember "Hot Lips" Houlihan in MASH? - and Ming the Merciless from Flash Gordon. Then there were the double acts: a lady with a urostomy and a colostomy calls them Fred (Flintstone) and Barney (Rubble), a husband and wife who both have stomas call theirs Rosie and Jim. Even films get a mention: Alien, Chitty Chitty Bang Bang, Bilbo Baggins from Lord of the Rings, and Harry Plopper.

Volcanoes featured quite a few times: Etna: "always erupting" and Vesuvius, in one case "unpredictable and explosive", in the other "rumbles and grumbles come from inside, sometimes it spits out foul-smelling gases and frequently pours out lava". The noise it sometimes makes gives some stomas their names: The Little Raspberry because "that's what it blows." and Toad (in the hole) because it croaks.

Now for the bit you've been waiting for... The Nominations are...

Eight names that need little explaining (In alphabetical order)

Albert (after my father-in-law, who was always a pain in the...!)

Arthur (pronounced Ahfar as "I only have half a bowel.")

Horatio (Hornblower)

Little Iffie (Iffie will or Iffie won't)

My appliance of Science

Napoleon (Stomafart)

Percy (In hospital the nurse's favourite line was 'You must persevere!')

The Privy Purse

And now five more where the connection between the name and the stoma isn't quite so obvious.

Colin

I had my colostomy in February 2006. My husband, whose name is Colin, has been a tower of strength. He gives me lots of support. Being a happy go lucky sort of guy he makes light of the funny noises that come from my stoma now and then. Sometimes he jokes and says, 'Stand back there's a trains coming' or 'What tunes are we playing now?' or he will look completely shocked, turn his eyes to my stoma and say 'Don't talk to me like that.' It is all said in jest and designed to help me cope with the embarrassment that I still have problems in coming to terms with at times.

Recently, during an episode when my stoma was particularly noisy, I managed to jump in first and blamed my husband for making the noises. We laughed so much I decided I would name my stoma after my hubby. So now I don't need to feel embarrassed any more. Whenever my stoma makes a noise I say 'Colin don't make that noise' or 'Colin shut up' Of course people think I am talking to my husband and he gets the blame. Sometimes I give Colin a little pat and say, 'Thanks' - to my husband that is - not my stoma

Dooper

I've been a Colostomate since May 2005. My stoma is known as Dooper as in "Super dooper". At the time of my diagnosis of rectal carcinoma in November 2004, my wife and I had to find a way to tell our daughters who were fourteen and eleven at the time that Dad would be going into hospital for surgery. I suppose not much of a problem for most, but our girls both have Down's Syndrome, so we had to come up with the truth in a simple and practical way!

In discussion we said to the girls that Dad had a "poorly" "Bum/Bottom" and that the doctors and nurses would help him get better but I would probably not be able to poo out of my bum like everyone else! It was at this stage that our elder daughter explained to her younger sister that Dad would be getting a "Super dooper" new way to poo!

To this day, if people stop us in the street to ask of my health, both girls readily tell them about Dad's "Super dooper" new way to poo! And if pushed will even tell of Dad's packets which he poos into.

Grace

I have had Crohn's disease from the age of 25. During that time I had eight operations and have tried just about everything. Then my consultant said he thought a stoma would be best for me; I had no muscles left in my back passage. So Grace was made in November 2004. Why Grace you may think. I had been very incontinent for a very long time and I wanted to be graceful. When my op was done - around Christmas time that year - I was going around Asda and one of the night nurses shouted over to me, 'How is Grace?' I answered, 'She is fine and I am coping well. I have my ups and downs like everybody else, but it is the best thing I have done.' The care I had in hospital was brilliant. The stoma care nurses were very caring and are always willing to help me.

Last year we went abroad for the first time to Ibiza, where I won "The personality lady of the week." Since then we have been to Tenerife, Lanzarote, Torquay and Paris and we have booked two more holidays. Life with Grace is great. I hope this letter will help other people to acccept a stoma. I will be sixty-six years old in March and also suffer from Ankylosing Spondylitis and have limited mobility, but my prison door opened when I got Grace.

Polly Pocket

When I had my operation in December 2005 my five year old granddaughter, Caitlin, came to hospital to see me but was very worried about Nan's tummy so I asked her to help me give it a name. She asked could she see it as then she could call it something. So I pulled up my nightdress. 'Oh it looks like a pocket' said Caitlin. I want us, Nan, to name her Polly.' So my stoma's called Polly Pocket and whenever I am with her and need the bathroom, we say 'Nan's going to see to Polly.'

Tweed

I was rushed into hospital with a burst bowel and septicaemia. My lungs were drowning in green fluid. To the rescue came a wonderful young consultant surgeon, Mr Harris. At our first meeting he gave me just two days to live and I just begged to die. He ignored my pleas and here I am.

While in intensive care I was visited by a stoma nurse who told me all the mysteries of what had happened and how to cope. In honour of the wonderful Mr Harris's skill I have named my stoma Tweed.

Please help us decide the winner...

The winners will be announced in the Summer issue of Tidings.

Register your vote...to reach us by 7th May 2007

E-mail us at
beryl.goddard@colostomyassociation.org.uk

or simply cut out and fill in the voting form below and post to:
Colostomy Association
15 Station Road
Reading
RG1 1LG

"Name your Stoma" Competition

Best Name - I would like to vote for (tick one box only):

- ☐ Albert
- ☐ Arthur
- ☐ Horatio
- ☐ Little Iffie
- ☐ My appliance of Science
- ☐ Napoleon
- ☐ Percy
- ☐ The Privy Purse

Best Letter -I would like to vote for (tick one box only):

- ☐ Colin
- ☐ Dooper
- ☐ Grace
- ☐ Polly Pocket
- ☐ Tweed

Name: ____________________

Address: ____________________

____

____

____

Are you a friend of the Colostomy Association? Yes/No
(Delete as appropriate)

If No would you like your name to be added to our data base and receive a copy of Tidings quarterly? Yes/No
(Delete as appropriate)

Dear Nurse...

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

Q: *I have been having a problem with my motion not dropping into the bag. It just sits around the stoma and I am very conscious of a bulge, which I think everyone will notice. It also seems to block the hole into the bag, so that the motion pushes its way behind the flange.*

My stoma nurse suggested putting some oil in the bag. I have tried this, but it does not seem to help. Could you please advise me as I am finding this quite distressing. It is having an effect on my confidence as I am always worried about leakages.

A: The problem appears to be due to 'pancaking', whereby the motion sits at the top of the pouch instead of dropping down. This can sometimes be helped by using oil in the pouch but is such a common problem that a special lubricating gel and sponge cubes are now available on prescription for use in the pouch. Information regarding these and the code numbers for ordering them are available from your Stoma Care Nurse. These should be used in conjunction with the filter cover which is now supplied inside all boxes of pouches. This can be stuck over the air filter to allow air to remain in the pouch allowing the motion room to drop into the bottom of the pouch.

Q: *My wife and I are both aged eighty-six. In June 2006 she had an operation for a perforated bowel, resulting in a colostomy. I have since been her sole carer. Her digestive system has now settled down to a fairly regular pattern so that the stoma pouch needs changing only once daily. I put a new one on each evening when she retires. Nothing much happens during the night and it gradually fills as motions occur during the day. However, on seven occasions usually during the day, there has been what I can only call a diarrhoeal outburst.*

At first it was not difficult to find the cause, for instance, an unwise helping of prunes to try to relieve constipation. Experience has taught me what to avoid but in spite of great care being taken with the diet there have recently been several inexplicable 'accidents'.

I cannot help feeling that this is because I do not know nearly enough about what food I should give her – I have a very rough and ready list of some things that soften stools and others that harden them but this warns that 'everyone is different' and the list is for guidance only. I would be very grateful for any advice you could provide.

A: It is difficult to give specific dietary advice for colostomates as everyone is different. The advice is usually very general and suggests that individuals try different things to see how, if at all, they affect them. I would suggest adding in foods individually and try them for several weeks to see if they affect you wife's output at all. If you find certain foods do cause a looser motion you can choose to avoid them altogether or be prepared for the resulting loose motion and possibly change the pouch an extra time. If you want more individualised advice you would need to ask your GP to refer your wife to a dietitian who will be able to assess you wife's needs in more detail.

Q: *I had my bag installed five years ago at the age of sixty-nine, after many years of treatment for haemorrhoids (injections, bands etc). An operation carried out to, hopefully, solve this long term problem proved unsuccessful and I found myself, within months, having to digitally evacuate my bowel (as my medical notes so delicately put it), due to the anal sphincter not functioning properly. This went on for many months. From the depths of my depression I came to the decision that I would go for the only option now offered me – a colostomy. I found relief and have no regrets. Apart from the occasional 'phantom' anal pain from time to time, I was managing my life reasonably well – that is until now.*

The 'phantom' pain has become a regular, daily occurrence. Getting out of bed and standing can produce this spasmodic feeling of desperately needing to empty my bowel from the rectum (which is impossible) and trembling from pain. This happens at anytime throughout the day. My hobbies of gardening, water colouring and sitting at my sewing machine have all come to grief because of this.

My late father had treatment for haemorrhoids for years and now my eldest daughter is undergoing treatment. Could this complaint run in families? I now attend the Colo-rectal out-patient's clinic seeking further treatment. I read the autumn issue of Tidings and sympathise with the gentleman correspondent, who has a similar problem. I wish I could offer helpful advice but am unable to do so. Perhaps you or other colostomates can help.

A: Phantom rectal pain following removal of the rectum is quite common and most people manage to adapt and live a full life with it. However there are some people who require review by a Chronic Pain Consultant to discuss the relevant options available to try to help relieve the pain or at least make it more bearable. I would advise anyone who suffers from phantom rectal pains and who is having difficulty adapting to it to ask for a medical review with a suitable practitioner to see if they would benefit from referral to a pain specialist.

Q: *I am writing to you because I am desperate. I had an end colostomy formed in November 2006 for rectal cancer. Like one of your correspondents the thought of the colostomy was worse than the illness. Only the stoma nurse gave me hope by telling me about irrigation. I could do this. I would get my life back.*
In January this year I was given permission to start. Imagine my despair now when I cannot make it work for me. I am a fit, able, capable woman but my bowel will not respond. More water or less water (one to one and a half litres), faster or slower (five

Dear Nurse...

minutes to fifteen minutes) every other day, nothing happens. The water goes in but only about 50% comes back. Brown liquid, no solids. I try to drink a lot in case my bowel is absorbing the fluid. But to no avail.

I stay in the bathroom for about an hour and fifteen minutes and come out at about 5pm in the evening. Two hours later the stoma starts working and continues until bedtime. If I am lucky I may have a reduced output the following day. At no time are the stools formed, just a sticky, pancaking mess.

Without the irrigation I have to change my bag up to six times a day - with it, perhaps four. I have started to take Imodium tablets and/or Kaolin to try and slow everything down and to make the bag contents more solid, but with limited success. I never had any problems with my bowels before my operation and my diet has not changed. Why now is my output so prolific and like toothpaste?

My surgeon assures me he did not take out very much colon and my stoma nurses are as defeated as I am. I have telephoned your helpline and spoken with other irrigators but none have experienced what I am going through.

Is there anyone, anybody at all who has an answer to my problem.
Why won't it wash out my bowel?

A: I am sorry you are finding that irrigation is not working for you. Unfortunately this type of stoma management is not suitable for all patients and there are many other patients out there who have tried irrigation and found it to be ineffective for them. Some of these people have returned to using their stoma pouch without any problems, whilst others have found some benefit in using the Coloplast Conseal Plug to control their output. By the sounds of the problems with output you are having, the 'plug' would not be an option for you as it does not work unless the output is solid or semi-solid at least. However, it may be worth seeing your Stoma Care Nurse to review the products you are using and to discuss the Conseal Plug, especially if you find the use of Imodium or Kaolin is thickening the output.

Experimenting with your diet may also help, as, although your diet has not changed since your surgery, your gut has and therefore different things may affect you differently now. For instance some people find that citrus fruits, green vegetables and fruit juices make the output looser whilst bread, pasta and rice can help to thicken the stool. Also Fybogel may help. It is taken in a drink twice daily on a regular basis and some people find this helps to regulate and thicken the output.

Alternatively if you are unable to change the output consistency with diet or medication it may be worth you trying something placed into the pouch to thicken the output once it has exited the stoma. You can get more information regarding these products (Gel-X, Morform) from your Stoma Care Nurse.

I hope this is of use to you and wish you all the best in the future.

Please send your medical questions or any queries about stoma management to:-
Colostomy Association,
15, Station Road, Reading RG1 1LG
or e-mail
cass@colostomyassociation.org.uk
We will forward them to Julie Rust and publish her answers in the next issue of Tidings.

For a warm welcome visit us at...www.colostomyassociation.org.uk

You may already have seen our brand new website, but if not...log on!

There is a wealth of information available. Whether you are looking for a support group to join or want to know of any events near you, you will find it here.

There is a full list of literature and fact sheets that are available as well as lots of other useful information.

Nurses and professionals – You can now order extra copies of the Tidings magazine and other literature on line.

If you have any comments about the website or would like your support group/event listed, please contact head office.

A warm welcome to all

home
meet the trustees
mission statement

A warm welcome from the trustees of the

colostomy association

dedicated to colostomates and their carers

“Cycle for life” was a charity organisation formed about eight years ago in Nairobi, Kenya. On my usual Sunday, keep fit, leisurely ride, with friends, an idea just cropped up: “Why don’t we cycle to raise funds for food for the less fortunate?”

Cycle for Life...

I am a thirty-nine year old male and have always led a very active outdoor and sporty life until that unfortunate day, March 16th 2003, when my surgeon broke the shocking news that my only chance of survival was to have an ileostomy operation. Until then, I had never heard of a stoma or knew what it was! I spent the pre-op days getting as much information as I could to prepare for my future and the remaining years of my life. I must mention here that, due to my family’s extreme support, I was back to normal life within a short period and today in some ways feel fortunate - I guess just being alive is more important than anything else.

“Cycle for life” was a charity organisation formed about eight years ago in Nairobi, Kenya, my birth place. I was with a few friends on our usual Sunday, keep fit, leisurely ride, when an idea just cropped up: “Why don’t we cycle to raise funds for food for the less fortunate?” Hence the inception of ‘CYCLE FOR LIFE’.

We had done two previous cycling expeditions to raise funds but this was going to be different. We would be cycling from one country to another (Kenya to Tanzania). Also, I’d moved to the UK and got used to the cold weather here - but more importantly, I now had a STOMA!

This was going to be one of the most challenging charity cycle runs partly due to the bureaucracy of two different countries: forty cyclists from UK and fifty from Kenya, sorting out visas and crossing over the border on cycles, organising accommodation, security, etc. There was more admin work upfront than for the actual event, which was planned for the Easter holidays 2005.

Coming back to my preparation, I must thank the stoma nurses at St. Marks Hospital who provided all the best advice and support. To be honest, these ladies make us so comfortable in coping with a stoma that we tend to believe that it’s just one extra normal organ in our body! Anyway, my utmost worry was the hygiene and lack of toilet facilities in that part of the world.

We set out on March 24th with over ninety cyclists and thirty volunteers providing various support i.e. food, drinks, medical help, security etc. We even had chefs who provided hot meals in the wilderness by the side of the road, serving nutritious energy-rich meals and snacks in the African heat. Our route was to take us from Nairobi, the capital city of Kenya, through the slopes of Africa’s highest mountain, Mt Kilimanjaro, spending a night at Amboseli National Park. We would cross over to Tanzania, through Namanga, then on to Arusha, where we were to spend the second night. The third night we would stay at Lake Manyara, before finally moving on to the Ngorongoro crater in the world renowned Serengeti National Park.

As we were to cycle from early dawn to just before dusk, due to security and accident prone roads, each day we had to start early and pace out accordingly. For me, the biggest worry was how I was to cope with my appliances in the total wilderness with no facilities at all. Relieving a call of nature in the open behind a bush or a tree, if you can find one, is a normal thing in that part of the world, but my anxiety was totally different from other UK colleagues, who I guess got used to it after a while. My only peace of mind was that, as I was using a two piece appliance, I would not have to expose my stoma to any flies, insects etc; I was worried about picking up an infection.

On the first day, due to the unknown challenge ahead, I was too stressed to eat at all till evening, just surviving on fluids to avoid emptying my bag. I knew too well that my only option was to empty the bag behind a bush and on certain routes it was all vast open wilderness with nothing in sight for miles! On the second day in Tanzania, it was much better and also, with each day, my confidence grew, but I still controlled my food intake. I planned to empty the bag once daily using all the expert advice on hygiene from the stoma nurses, and without anybody knowing my condition as well. That was a challenge in itself! Anyway such wonderful mother nature in view - scenic mountains, lakes, wild animals - and the warm hospitality of the local people made it all the more easy for me, by diverting my mind away from my stoma.

Coming back to the charity details, we raise funds to provide hot meals for people in the various slums of Nairobi for the rest of their life. We have set up a place where all meals are prepared and dispatched to different parts. At the moment, we are feeding two thousand people everyday day of the year. I believe my greatest inspiration and determination came from the belief that all my efforts will provide somebody, who does not know where his next meal will come from, with a plate of hot food! We managed to raise £180,000 in this event with the biggest chunk coming from the group of UK cyclists, some of whom were visiting this part of the world for the first time. To most of them, it was one of the most memorable events they had ever taken part in, taking into account all the media hype about insecurity, no infrastructure etc.

We are already planning the next event for Easter 2008. This time we are raising funds to build a thousand boreholes to provide water to various villages where people travel miles on foot just to get that precious drink. We will be cycling this time in South Africa, from one city to another for an even a bigger challenge.

When I see all these less fortunate people, it gives me more will power and the belief that living with a stoma is not the end of the world. People out there are in worse state than some of us. This event in particularly has changed all my character and led to acceptance, since that day, over three years ago now, when I heard, in the ringing voice of my surgeon, the word stoma for the first time.

Sanjay Hirani

Sanjay would like to hear from other young ostomates and has asked us to publish his e-mail address, sanjay1@mail.com, in case any of our readers in their thirties or early forties would like to get in touch with him. Ed.

Reader to Reader...

Dear Tidings
Following a long period of ill health I had my operation in December 2006.
I do not know anyone else with a stoma and am writing to Tidings to ask if there is another reader who would like to become a friend or a pen friend.

I am in my late fifties and have two grown up children and two fast growing and energetic grandchildren. My interests include antiques, attending car boot sales and walking in the country.

As there are no support groups in North Lincolnshire, I would also be interested in setting up a group of like minded people to help each other.

Yours sincerely
Ann

Dear Readers
I am 56 years old, 5ft 3in, a redhead, non-smoker, non driver and have two grown-up children. I live and work in Somerset. I had my stoma done in June 94 and was given a new lease of life.

My interests are motorbikes (got the gear), rugby, walking, music, days out, bike shows and racing, cooking, museums, theatre, stately homes and meeting people. I prefer to meet the person rather than talk for hours on the phone.

Best wishes
Celia

Dear Readers
I class myself as being a very lucky lady; I am aged 64 and live in Bedfordshire, married, three daughters, five grandchildren and the owner of two adorable rabbits. Lucky, not once but twice. I suffered a heart attack and could have been long gone. Then for reasons unknown I developed cancer some three years ago and became a colostomate. I was very thankful to be living in such a time when this procedure is widely recognised but, sadly, all too frequently being performed.

What is the point of this letter? My husband doesn't do 'the arts' so please read on...
I am looking for company - an ostomate would have an understanding of my requiring a little more time in the "Ladies" - to visit an art gallery/museum in London and provide a male view-point on any forms of art. On the off chance that there are some 'arty males' out there I leave my contact numbers.

Sincerely
Pat

If you would like to contact Ann, Celia or Pat write to Head Office and we will pass on your letter.

Illogical Bowel Syndrome...

The 8th August 1974 was a life changing date for me, although I wasn't immediately aware of it at the time. My husband, myself, our three sons plus my mother were travelling back from a holiday in North Devon, and we were all looking forward to arriving home at tea time. Alas that was not to be, for we were involved in a serious car accident at junction 15 on the M4 motorway. Fortunately my husband, sons and mother escaped with minor cuts and bruises, but I was thrown from the car and suffered multiple fractures of eleven ribs which pierced my lung.
I also dislocated the fingers of one hand and suffered severe concussion.

During the next three weeks I remained on a ventilator in the ITU unit of Swindon hospital, and it was touch and go whether I would qualify for heavenly wings, plus a halo of course. However, I was lucky and, due to the amazing skills of both doctors and nurses, I survived. Once I had progressed to a normal ward, I became aware of the disturbing fact that food would not stay put for too long and, on enquiry, was told by a nurse that it was due to the trauma. I was, at that time, too happy to be making such good progress to worry very much about this problem and I assumed that, once I was out of hospital care and back home, all would revert to normal.

Eventually the happy day arrived when I was really on my way home. It took me many months of further treatment to fully recover but unfortunately the colon problem was as persistent as ever. The day came when I was finally assessed by a consultant. I was told firstly how lucky I was to have survived - which I already knew -and secondly that I would recover 99% from all my injuries, but I would never lose that, and he pointed to my stomach, meaning the now familiar condition of anything I swallowed whizzing through my system at the rate of knots!

I am afraid I was very sceptical about his forecast and really believed that in due course my food intake would stay put as it used to before the accident. I was to find out that he was quite correct and my own doctor confirmed that the condition I had was called Irritable Bowel Syndrome commonly known as IBS. To alleviate the symptoms as much as possible I was given various potions and pills all of which my system ignored completely. Finally I was prescribed codeine phosphate, and one little tablet taken in the morning assured a complete day of bliss when my colon behaved impeccably. So on the occasions when we were invited to family get-togethers or special days out, I duly swallowed the little miracle pill and all was well for the whole day. However, the bliss was short lived as the following day, having missed a days action, my colon whizzed merrily back into disorder-mode plus, but the one day respite was always a welcome relief.

Of course, like everything else, as years creep by all ailments become a little more severe. By the end of 1980 I found that, despite being on a very restricted diet, the severe symptoms of IBS still persisted;
I also had another problem which accentuated the IBS. My first two sons were very difficult births; I had a lot of internal stitching, and over the years muscles became lax. In the end I was experiencing not only bouts of diarrhoea, but I had very few muscles left to combat this - disastrous to say the least!

Eventually, I went to see a very caring gastroenterologist who treated me over a period of about ten years. He first prescribed Colestyramine, a powder which is dissolved in water, and for the next ten months life was much better as this treatment was very effective indeed. I had to stick to bland food: very few vegetables or fruit, in fact the list of things I couldn't eat was endless, but of course I was aware of most of them from bitter experience. However, sadly after ten months my colon became used to this treatment, and it wasn't quite so effective any longer. Other drugs prescribed had little or no effect either and so, after five years of trying to make life as loo-free as possible, the consultant told me that I should really contemplate having a colostomy.
I was shocked and dismissed the idea completely and soldiered on with a life that was dominated by bouts of diarrhoea; the smallest room in the house was the one I occupied most. My first thought when I was invited anywhere was: "Will there be a loo nearby? What will there be to eat and how will it affect me?" In the end I found that it was truly hit and miss as to whether any outing, however mundane, could be accomplished without worry or mishap. Of course there was the point that as soon as I found myself anywhere without a loo in sight, or within short walking distance, the psychological side of things took over from the physical and I immediately needed one - believe me every loo in every part of all the towns around me was firmly lodged in my head. It was whilst on a particularly disastrous outing that I had to admit that I could no longer go on living this way, and began to seriously think about having a colostomy.

It is very difficult to actually put one's hand up for a serious life changing operation and so it took me quite a time to say "Yes", but in January 2005 I finally went into hospital for a colostomy. Prior to the operation I was told by the surgeon that if the IBS was in the lower part of my colon I could actually lose the symptoms, but unfortunately that wasn't the case and I still battle on with the irritable (illogical) colon. I quite often get optimistic and think I have found a part solution - it seemed a lot better when I started drinking only bottled water, and then squares of jelly stopped its progress for a while as well. However, it still remains an enigma: sometimes I can eat food which I think will produce constant loo visits and my stoma surprises me by behaving itself, other times quite bland food will cause an upset. Yes, it is amazingly illogical, but I guess I will just have put up with it - unless any reader has a bright solution to this problem.

Having a colostomy has its drawbacks, but for me one enormous benefit – I can now go for walks, enjoy shopping trips, and look forward to days out without having the word "Ladies" in the forefront of my mind, and after twenty-two months that still remains a novelty.

Peggy Farley

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Readers Writes

Dear Tidings

As a new colostomate, I can’t tell you how much the magazine has helped to allay my fears. It has answered many questions and the advice is invaluable. I was worried about putting the waste products in the “wheelie-bin”. Then lo and behold in the letters page I saw correspondence on this very subject. Your advice was to get in touch with the local council. They wanted confirmation from my colostomy nurse, but within two days they had arranged delivery of an incineration bag, which is collected every Monday.

This is just one instance. I’m so grateful. I must admit I still get very tearful, but it is helpful to know there are so many of us colostomates.

Thank you. Keep up the good work.
J.N.

To the Editor

Congratulations on producing an excellent edition. I found the information on irrigation very informative. Should the government get its way a lot more of us will have to consider this method of managing our colostomies.
At present I am using three to four bags a day as a necessity. I don’t know how I'd cope on a box of thirty a month! I think most of us are aware of the cost of appliances and are as economical as possible! The Code of Practice reminds us of how to act responsibly. Keep up your good work on the consultations to ensure that our needs are not eroded. How about something on sexual dysfunction in men after surgery in a future edition?

G.D.

In a future issue we are planning to address the issue of sexual dysfunction in both men and women as well as psycho-sexual problems and body image. Ed.

I read your 'Tidings' every word, cover to cover, and it's been a great comfort to me to know that I'm not the only one who has problems. I had my colostomy, due to colon cancer, five years ago. The first four years were a nightmare; my pouches wouldn't stay on. I had a very loose output, which caused me no end of trouble and embarrassment. I had to change my bathroom floor for a washable one. I was changing beds in the middle of the night. I was rushing home before anyone could see it seeping through my clothes. It was all very distressing.

However, I had the chance of a reversal last year. Sadly the operation went terribly wrong and I had a loop colostomy formed, to be finished off at a later date. I was very ill for a few months. then came the time to have the closure, but it was thought by the experts to be too risky, so I am now back with a stoma like I had in the first place.

While I was in hospital I was given different pouches and I am still using them now. They stick to me like glue and not one accident - absolutely marvelous. My point is that you don't have to put up with these problems. You DO have a choice. You are given your supplies by the Company that sponsors your Stoma Nurse. There are a lot of different products to be had so, if yours doesn't suit you, ask for samples of others, or even change your supplier.

Thank you again for your wonderful magazine, I don't have money for donations, but I have got 'everyclick' as my home page now.

P.S.

Dear Friends

I am writing to say how much I look forward to, and enjoy, Tidings and to tell you the name of my stoma. I christened her Winnie, as in “Winnie the Pooh” but without the h! If out with friends and I need to change, I let them know by dropping the name Winnie into the conversation. This way we all know where the next stop will be.

I am seventy-one years old and have put up with Winnie since 1991. I still haven’t come to terms with her as it’s so unpredictable. Being alone and a non-driver, the ‘highest mountain’ I climb is risking a bus trip to the next town to shop.

I admire all the positive people who say, ‘It hasn’t altered my life much’. Maybe if mine had been because of a life threatening illness, I might feel different. I had diverticulitis which was, and I quote, “treatable”. When I came round they had “treated” me to a life with a permanent colostomy - now plus a hernia.

Sorry to moan and sound so self-pitying, but not every colostomate is the same, and I feel certain there are many more like me, who plod along in silence, admiring the ones who can get on with their lives. Once again I will say how much I look forward to Tidings and read it cover to cover. Keep up the good work.

Best Wishes
M.F.

Glad Tidings!

Like SB who wrote the letter on page 42 of Issue No 4, I too have a colostomy for reasons unconnected with bowel cancer. And again, like your 85 year old correspondent, I have never seen any reference to ‘other causes’.

In my case, after years of misery during which various diagnoses i.e. dyspepsia, appendicitis, attention seeking, mental instability etc. were put forward, a hospital research unit diagnosed the failure of the sphincter muscle, which controls emptying of the bowel. Hypnosis was suggested as a possible aid.

Admission to A & E in November 1998 led to the formation of a colostomy. Regrettably, the emergency surgeon failed to notice the research unit’s report and I was given a temporary stoma which over the years resulted in a blocked rectum with minimal output into the pouch. The accumulated ‘rocks’ – termed as such by the surgeon – were removed in March 06 and it was only in September 2006 that the consultant finally admitted the ‘wrong’ operation had been performed: it should have been a permanent colostomy. I now have to perform enemas since internal mechanisms are of no help.

I find the assumption that all colostomies are due to bowel cancer somewhat off putting and will probably make this donation my last. Perhaps it may be expedient for your nurses to investigate causes other than cancer for the malfunctions which S.B. and I have brought to your attention. I realise of course that cancer sufferers get a much more ‘sympathetic’ response and presumably would begrudge space given over to this.

Yours sincerely,
M.C.

In 2002 Tidings carried out a survey of its readers. Of the 2,800 colostomates who returned the questionnaire, two thirds reported that their stoma was formed due to cancer. The remaining third gave a wide range of reasons for their stoma: diverticular disease and incontinence being the most common. So, Yes, we do appreciate that not all colostomies are formed as the result of cancer. Tidings aims to include a wide range of information and reflect the views of all colostomates as I hope the articles on pages 20 & 38 and the letter on page 42 will demonstrate. We would also welcome suggestions for subjects we might cover and contributions from readers whose colostomy was formed for unusual reasons. Ed.

Dear Friends

I am 83 and in 1991 I had a blockage and went in for a resection but ended up with an end colostomy. I did not have cancer and have no problems. I have given up going abroad – as there’s no need to book up months in advance to holiday on the south coast.

I have tried many samples but for a long time have been using the same appliance, a large drainable bag with a plastic clip on the bottom and no filter as these tend to let all the air out. Under my trousers I wear a pair of ‘Asda’ thin high-waisted shorts (£3) I roll up the bag and tuck the leg of the shorts into my boxer pants.

When I go out I carry my radar key and a small thin bottle which I can fill with water to wash the bag out, so that it is always clean. I have no problem finding a wheel chair toilet – just wish that the logo was altered to save us black looks.

Stan Weston

Dear Editor

My wife, who had a permanent colostomy following rectal cancer in 2000, finds that other colostomates’ experiences - some traumatic - put her own situation into perspective.

She also welcomes the advice and helpful comments from the nurses, as well as finding the advertisements useful in investigating other types of accessories. As her husband (and helpmate!), I find the subject matter has improved my own knowledge and interest.

Congratulations on your magazine with its constantly positive tone.

Yours sincerely,
P.S.

I am an expat living in Spain and have been resident here for nine years. In the past twelve months I have had two operations; the first was a stomach resection, called a gastric bypass, I believe. Then last summer, I had a colostomy. Both these operations were due to internal bleeding, probably caused by radiotherapy to cure prostate cancer.

There seems to be nobody I can speak to in Spain regarding my colostomy. My surgeon and doctor both seem to be general doctors and not stoma specialists.

It would be great if there was someone I could turn to for advice. Any help you could offer would be gratefully received.

Regards,
D.S.

We have had several queries about holidaying in Spain or moving to live there permanently. Therefore, on page 28 of this issue of Tidings we include an article written by the chairman of The Expatriate Ostomates of Spain, a registered charity run by ostomates to help other ostomates who live there permanently or are just visiting. Ed.

Dear Editor

Thank you for sending my son the Tidings magazine since his colostomy operation in December 2005. You may be interested to know that despite having a learning disability (Williams Syndrome) he is independent in his stoma care, thanks to the wonderfully patient stoma nurses at our local hospital. He is 38 years old, and, having read some of the magazines, has decided that it is not for him. However, as parents and carers, we feel there is so much to help us that we would like to continue receiving Tidings. Accordingly, I enclose cheque for £12.

Yours sincerely,
C.N.

Dear CA

I read with great interest your write up about medications. How very true, as I found out for myself last November. I had been having severe stomach pains for two days and feeling very sick. I saw my doctor and was rushed to hospital with a blocked bowel.

Thankfully, I recovered within three days and was sent home. I had been taking co-codamol and amitriptyline for arthritis; the doctors at the hospital told me I should never have been given these and I will never take them again.

Many thanks for a great magazine, it is a truly uplifting read and gave my spirits a great boost.

Yours sincerely,
B.M.B

Readers Writes

... our last letter is from a reader who wrote to say what many of you have also told us: "Not all colostomates want to climb mountains."

Dear Editor

I would like to offer a positive view of living life with a colostomy that doesn't involve any mountain climbing, marathon running or sailing across oceans. There are no visits to Australia in sight and no signs of trekking across the United States of America. I have in mind a nice cup of tea and a biscuit this afternoon and a night out at the cinema later on.

I have been prompted to write to you after reading the winter 2006 edition of Tidings. There was a letter from S.B. who had a colostomy following a prolapsed rectum. My story is similar. After a childhood plagued by bowel problems, I had a prolapse when I was a teenager. This was repaired when I was twenty using a technique of inserting bands around the prolapse to hold it in place. The operation was a success but resulted in extreme problems with constipation. I was in full time employment and this created difficulties as I was stuck on the loo for hours each day.

As years progressed my days were spent taking doses of laxatives and planning the highest fibre meals I could manage. My social life was almost non-existent, I had to drop down to part time work and eventually I gave up work altogether. I am married with two children and in 1995, at the age of thirty-six, the situation had deteriorated so much that I chose to have a colostomy.

This has improved my life in so many ways. I am now forty-seven. I have a part time job, a good social life and much more freedom now that I don't have to plan my life around visits to the loo. The only problem I have with my colostomy is noise. My stoma care nurse is unable to resolve this as it is due to the underlying condition of my gut. However, I have made adjustments to my working and social life to allow for it. I like to keep my private life private so chose only to tell relatives and close friends about my colostomy. As the noise is most obvious during the day, I socialize in the evenings when it is less active and therefore quieter. Likewise, I work in the evenings. It has been pointed out to me by well meaning friends that I would have more opportunities for promotion if I worked during the day. While this is probably true, I would be very embarrassed by the noise and would find it stressful. So why put myself through that just to achieve promotion? To me, getting back to work is the achievement, so I think I have a pretty good outcome there!

Realistically I think living with a colostomy will present difficulties from time to time but for me these are so few, compared to before my op, that I am willing to work my way around them as I have explained. There are many articles written in magazines about people with colostomies who achieve great things such as climbing a mountain, running a marathon and sailing an ocean. I am happy to admit that I will never be one of these people. My achievements are the normal things of family life that were not possible for me before my op: eating a meal without it resulting in stomach ache, having the energy to go swimming twice a week, a night out with my husband or a trip to the cinema with my children. I now have time to sit and just read a book or watch TV because I don't have to spend hours each day on the loo. A holiday once a year in Cornwall is much more relaxing to me than the prospect of flying halfway around the world to go trekking. Not for me the airport delays, the possibility of missing baggage and colostomy equipment and searches by security officers at check-in. Cornwall for me every time!

I realise that there are well meaning people who will think I am missing out on life and offer advice on how to live with a colostomy (even though they may not have one and possibly don't understand all of the issues). Might even advise me to go out there and do great things (that mountain again. Aargh!).

I think they look at it the wrong way around. When, as a twenty year old you spend up to four hours a night on the loo and you get up next day and go to work only to repeat the same experience the next night and the next, as a thirty year old you are no longer capable of holding down a job and as a thirty-five year old every social occasion is spent counting down the hours till you can get home and go to the loo, then I would say that far from missing out on life I have got mine back. I am happily married with two lovely children, I am able to have a great time going out with my friends and I have a part-time job that I look forward to in the evenings. My life is probably never going to be spectacular in the normal sense of the word but I don't think that matters as long as I enjoy living it. So I would like to say good luck and well done to all of those mountain climbers and trekkers. It really is a great achievement, but it's not for me. I think it's time for that cup of tea and a biscuit. Anyone like to join me?

Yours sincerely,
Julie

From Ed...

Dear All...

Thank you for your letters and e-mails. Please keep them coming and we will do our best to print them. Editing may be required for reasons of clarity or space. In the interests of confidentiality we will publish only your initials, not your full name, unless you give us permission to do so.
Ed.

Editing Team
Rosemary Brierley
Jo Mckenzie, Gill Herbert
and Beryl Goddard

Support Group in the Spotlight

Glasgow Support Group

L-R: Mollie Thompson Colostomy Association Volunteer and Maureen Anderson, Stoma Care Nurse Advisor.

Members of Glasgow's Stoma support Group enjoying Mollie's baking.

"Fittleworth Friends Self-help Stoma Support Group" has been running for just over a year. We started out with three or four members but have grown in strength and number. Mollie Thomson, Colostomy Association volunteer, came along to our very first meeting and has been a sterling supporter since the beginning. We now have twenty-five to thirty members- from the young to the young at heart- at various stages of recovery. The group meet once a month to provide support to each other.

We invite a speaker and an ostomy manufacturer to display products and samples and have coffee and the addictive, much talked about and consumed home-baking provided by Mollie! There is always time to speak with another ostomist which is by far the most valuable part of the meeting.

In summer, 2006, we enjoyed a bus trip to the seaside and the mandatory fish tea! The group have already started saving for this years outing! Who knows where we'll go this time - the sky is the limit with this outgoing group.

We also held a Christmas coffee morning with home-made mince pies and plenty Christmas cheer. No need to guess who provided all the pies and extra home-baking in order to help raise the enclosed donation! Our members, along with the members of the Edinburgh stoma support group, donated some raffle gifts which, along with Mollie's baking, helped us to raise a total of £135. As a result of Mollie Thomson's fantastic support, the group decided to donate this money in support of the CA.
We thank you for all you do in aiding the recovery of anyone undergoing stoma formation, and would like you to tell Mollie that we could not do without her, she is a staunch ambassador for the Colostomy Association.

Maureen Anderson
Stoma Care Nurse Advisor
Fittleworth, Glasgow

The group meets at the Fittleworth Care Centre, Unit 1 Riverside Business Park, Moffat Street, Glasgow G5 0PD on the first Tuesday of every month. For further details contact Maureen on 0800 783 7148

Put your group in the Spotlight. Write and tell us about it and we will do our best to include your article

Feedback from Spotlight...Guernsey Ostomates

After our last issue, when The Guernsey Ostomates appeared in the spotlight, one of our readers wrote to say:

"I was born in Guernsey 1933, and have lived on the mainland since the German occupation, but I go back every year for a holiday. We will be going again in March for our Golden Wedding and I have rung Dave Allen (the founder of the support group) and have arranged to meet him-another good thing about Tidings. Keep up the good work."
Bernard

News of local groups

The colorectal nurse specialists at Grantham Hospital - started a support group in September 2005. The group meets at the Kings Hotel on the third Friday of alternate months (January, March, May, September & November) from 10.00-12.00hrs.
The meetings are popular and attendance figures have remained high.
For more details contact: Bobbie Lee or Amanda Stuart-Stamp
01476 464822 (direct line)

Colo-Rectal Ostomy and Pouch Support (CROPS) Sheffield
The next meeting will be held on Tuesday 17th April from 2pm until 4pm at the Quaker Meeting House on St James' Street. It will be a patient information day with manufacturers and the voluntary associations present.
For more details contact: Shauna, Maxine or Sharon at the Northern General Hospital or call Gloria on 0114 2879503

Nottingham Colostomy, Ileostomy & Urostomy Support group
The next meeting will be held on Saturday 21st April from 10am until 12noon at Clinic 1, B floor, Queens Medical Centre, Nottingham. Shelley Biddles, Colorectal & Stoma Care Nurse, will give the final part of her series of talks on Stoma Care. The group meets regularly on the third Saturday of every month.
For more details contact:
Rosemary on 0115 982 7868

Ostomy Friendship & Support Group
King's Lynn Branch Meeting Dates for 2007:
June 2nd Sept 8th Dec 15th
All meetings are held on Saturdays, 2-4pm at the QEH Social Club.
Family and Friends welcome.
Refreshments, Raffle, Helpful Tips and Talks.
The Group is run by Patients for Patients, with Professional support.
For information about the meetings, or just a chat about your ostomy,
please ring 01553 770288, 01553 768271 or 01553 775698

Yeovil District Bowel Cancer Support Group
For date and venue of next meeting visit www.bowelcancersupport-yeovil.co.uk

If you contact us before 21st May we will publish the date and venue of your next Stoma Support Group meeting.

For a complete list of support groups visit our website at www.colostomyassociation.org.uk

Fundraising...get involved

Charity Dance in the Victoria Halls

Country Dance for the Colostomy Association

On the 17th of February the Helensburgh Branch of the Royal Scottish Country Dance Society held its annual charity Dance. The chosen charity this year was the Colostomy Association. The members of the branch had been selling tickets for several months before the event. As well as the main cash prize of £100 there was a good range of prizes: some given by the local dance classes, some by individuals and also donations by local firms. With a large prize list of fifty-five items the raffle was drawn under supervision while the dancing went on and the major prizes presented at the mid-time break. The presentation was made by Mollie Thompson. She took the opportunity to summarize the work of the Colostomy Association and its history and importance to patients with an all too common and poorly appreciated condition.

The dance itself was to the music of Neil Copland a very popular Scottish Country Dance Band who plays regularly both in Scotland and abroad. There were seventy-eight dancers in the hall. The programmme was filled with popular dances, both old favourites and from the new books. As well as local dancers there were dancers from Glasgow, Bearsden, Kilpatrick, Ayr, Tarbert, Dumfermline and Northern Ireland. The dancing got underway on time and they all enjoyed themselves - as evidenced by very few dancers sitting out any of the dances.

The only dancers missing out were the organising committee who were setting out the tea and arranging the raffle. A generous tea with sandwiches and cakes supplied by the members of the branch was too much to clear. The remains made up in pokes acted as a source of further donations to the Charity which had made over £1000 in total - an excellent and worthwhile evening.

John Maccallum

Your Fund Raising Efforts...

Readers may remember our young colostomate, eighteen year old Rhiannon Beckett, who wrote an article about her trip to Disney World in Florida for last year's summer edition of Tidings. At Christmas Rhiannon made her own greeting cards and sold them raising £20, which she has donated to the Colostomy Association. Well done Rhiannon!

Ruth Gardner held a coffee morning in February. Despite the snow, twenty-one people turned up. A fantastic £225 for the Colostomy Association was raised by Ruth and her friends.

Margaret Rowland sent us a donation of £200. Her colostomy was formed during emergency surgery for Diverticulitis in August 2005. When she saw her surgeon on 7th July 2006, he agreed to perform a reversal. As she waited for the operation she saved up a £1 a day. By the time it was carried out on 31st October 2006 she had saved £106 which her husband topped up to £200 to donate to our funds.

Future Fund Raising Events...

Plant Sale

Mr and Mrs D Ashe are holding a plant sale on 26th May 2007, outside their home in Cranleigh Drive, Brooklands, Sale. All money raised will be donated to the Colostomy Association.

Why not help us with fundraising by holding your own event?

The theme is a 'Pot Luck Lunch', to be held the first week of June.

The idea is for you to get together with family or friends and all bring along a dish. Think about it: for the price of an apple pie you could sit down to a feast fit for a king!

How do we raise the money?

There are two ways of raising money at this event, either charge everyone attending a set amount e.g. £5 or ask for a contribution to the Colostomy Association.

Some ideas we have so far include:

- Italian theme

Everyone is asked to bring an Italian dish. This could be anything from garlic bread to tiramisu.

- A formal dinner

Ask each person to bring a particular course: it could be their favourite starter, main course or even a cheese board.

- Bar-b-que

Everyone brings along a dish to be barbequed (weather permitting). The host could provide the drink or do the cooking.

- Coffee Morning

If a lunch/dinner seems rather daunting then provide tea and coffee and ask your guests to bring along a cake or scones. This would also work well at your local support group or workplace.

- Ladies Day

Get the men involved! To keep it simple you could have a cold buffet and ask the men to do the preparing. This could mean anything from a round of sandwiches to a cold meat platter. You can then sit back and relax and be 'Ladies that Lunch'

This is an ideal way of fundraising as you don't have to do all the work yourself; in fact, you could sit and enjoy a three course meal with very little effort.

Please contact us with your stories and/or ideas for this event. We hope to include a selection in the next issue of Tidings. If you would like any advice regarding this event, please contact head office and speak to Gill, Jo or Beryl. Happy Dining!

colostomy association

Support us...please become a Friend of the Colostomy Association

The Colostomy Association is an independent charity, financed solely on donations.
This means that we must seek ongoing support to ensure our important work can continue.
We would like to invite anyone with a colostomy, (permanent or temporary) and/or members of their family to become 'Friends of the Association'

With your help we really can make a difference...our findings show there are approximately 60,000 colostomates living in the UK and with over 6,400 permanent colostomy operations being performed each year - we need to be here for them!

Other ways we help...The Association continues to help colostomates who are experienced and those who are new to living with a colostomy. We produce a regular quarterly magazine called 'Tidings'. We have over seventy volunteers who are all colostomates willing to make personal visits to offer support. We provide informative literature, attend hospital open days, and offer a twenty-four hour helpline. Our web site is being developed to reflect all of the above and more! Importantly, we are involved in ongoing consultations with the National Health Service on your behalf and will keep you informed of issues that may affect you.

Donations...Single donations from individuals and fundraising events are always welcome and greatly appreciated. Your financial support has never been more important. With a continuing income and planned agenda, we can budget for, and carry out, the excellent work of the Colostomy Association.

Becoming a 'Friend'...A 'Friend' is asked to make a regular commitment of £12.00 (or more) to the Association each year, either by standing order, cheque or postal order. This will ensure that we are able to continue to produce four issues of Tidings per year - full of the latest news, product information, hints and tips and real-life stories from other colostomates.

This regular payment will ensure that there is always a helping hand for those who need it, now and in the future – including some colostomates yet to be born. There are many thousands of adults and children, who, now and in the years to come, will receive a life saving colostomy.

Please help us to reach out to them with support and encouragement

I want to become a 'Friend':

☐ I enclose a cheque/postal order for £12.00 (made payable to Colostomy Association)

☐ I have completed the Standing order form on Page 46
(please complete the standing order form overleaf)

☐ Please tick here if gift aid applies to your donation (see overleaf for details)

☐ Please tick here if you require a receipt acknowledging your kind donation

Note: Please ensure that we have your full name, address and postal code

Office Address: 15 Station Road Reading RG1 1LG Tel: 0118 939 1537 Helpline: 0800 328 4257
E-mail: cass@colostomyassociation.org.uk Web: www.colostomyassociation.org.uk
Registered Office: Mill Cottage Polwheveral Constantine Falmouth Cornwall TR11 5RW Registered Charity No: 1113471

Donations & Standing Order Authority

Please help the Colostomy Association to support other colostomates by making a donation - thank you

Please return this form to: Colostomy Association, 15 Station Road, Reading RG1 1LG

Title: First Name: Surname:

Address:

Postcode:

Tel: Email:

Instruction to your Bank/Building Society to pay by Standing Order

To the Manager (Bank or Building Society)

Address:

Postcode:

Name(s) of Account Holder(s)

Account No: Sort Code:

Please pay:

NatWest Market Place Reading Branch
13 Market Place Reading RG1 2EP

Account Name: Colostomy Association Ltd

Account No: 88781909 Sort Code: 60-17-21

The sum of: £

Amount in words:

Date of first payment:

and thereafter on the same day every **week/month/quarter/year** (delete accordingly) until further notice. Please cancel any previous standing order in favour of this beneficiary.

Name: (IN CAPITALS)

Signature: Date:

I want the Colostomy Association to treat:

The enclosed donation of £ as a Gift Aid donation

Signature:

You must pay an amount of income tax and /or capital gains tax at least equal to the tax that the Colostomy Association reclaims on your donations in the appropriate tax year. (currently 28p for every £1 donated).

Registered Charity No: 1113471

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(FREESTYLE® CURVEX® USER)

FreeStyle Curvex is designed to give you the freedom to live life to the full and is ideal if you have any leaks or a slightly recessed stoma, even if it is only on one side, or if you have creases around the stoma site.

FreeStyle Curvex, which is available in both closed and drainable versions, could be an effective alternative to pastes and washers and is also suitable for hernias.

With its unique Hyperflex® 3-D contoured flange, which gently moulds into the body shape, you'll be confident of a secure, comfortable, leak free fit giving you the confidence to live life to the full.

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For a free sample of FreeStyle Curvex Closed or Drainable please complete the coupon and return it to: **CliniMed Ltd., FREEPOST HY241, High Wycombe, Bucks HP10 8BR** (NO STAMP REQUIRED) or call the **CliniMed Careline** on **0800 036 0100** or visit our website **www.clinimed.co.uk.**

Mr/Mrs/Ms:________ Initials:________ Surname:______________________ Address:______________________

______________________ Postcode:______________ Tel. No.:______________________

E-mail:______________________ **Details of the current pouch you use:** ☐ One piece ☐ Two piece

Name:______________________ Code:______________ My exact stoma size is:________ mm

☐ I understand that this request will be handled by CliniMed 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.

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Upfront • News • Events • Fundraisers

International Ostomy Association Congress 2007

IOA's 12th World Congress will take place from 7th to 12th August 2007 at The Fajardo Inn Puerto Rico.
For further information consult the IOA website at www.ostomyinternational.org

Bowel Awareness Open Day

The Colorectal Nursing Service of Walsall Hospitals NHS Trust is holding an Open Day on Saturday 21st April from 12noon until 4.00pm. The venue is in the Upper Room, The Crossing at St Paul's, Darwall Street, Walsall WS1 1DA.

Stoma Care Open Days

The Stoma Care Nurses of Salford Royal Hospitals NHS Foundation Trust are holding an Open Day on Friday 20th April from 10.30am until 3.30pm. The venue is The Masonic Hall, Monton Rd, Monton, Salford.

The Stoma Care Nurses of Countess of Chester Hospital are holding an Open Day on Wednesday 25th April from 1.30pm until 5.30pm. The venue is The Ellesmere Port Boat Museum.

The Stoma Care Nurses of Royal Shrewsbury Hospital are holding an Open Day on Wednesday 16th May from 12pm. until 3 pm. The venue is Lord Hill Hotel, Shrewsbury.

The University Hospital of North Staffordshire, Outlook Group will be holding their annual Patient Day & Exhibition on Saturday 19th May from 1.30pm until 4.30 pm. The venue is The Stop Inn on the A34 at Cross Heath, Newcastle under Lyme.

Thank you to all the Colorectal and Stoma Care Nurses who returned our questionnaire. We had a very good response and are analysing the results and will be taking forward some of the suggestions.

SMALL ADS

Have you something to sell, or a service to offer to Ostomates

If you have an advert that you would like to place in our new 'Small Ads' section of Tidings, please forward details to Station Road by the end of May. Charges will be £5 for up to 25 words, £10 for 26 to 50 words and £15 for more than 50 words. The Editorial team will have the final say as to whether an advert is deemed to be suitable for inclusion.

Tidings

Dedicated to Colostomates and their Carers

FeedBack

We hope you have enjoyed this edition of Tidings and look forward to bringing you the next edition...We are always trying to improve your Magazine and welcome your feedback.

Tidings is your Magazine

If you have a story, poem, article, letter or any other item you would like to be included, please send them to The Editor via post. Alternatively e-mail to our contact details below and we will do our best to include them!
We look forward to hearing from you!

Colostomy Association
15 Station Road
Reading RG1 1LG
Tel: 0118 939 1537
Freephone: 0800 328 4257
E-mail: cass@colostomyassociation.org.uk

Visit our new look web site

www.colostomyassociation.org.uk

Helpful
Groups & Organisations

Other Ostomy Support Associations...

- ia (The Ileostomy and Internal Pouch Support Group)
  Freephone: 0800 0184 724
  www.the-ia.org.uk
- Urostomy Association
  Tel: 01889 563191
  www.uagbi.org
- National Advisory Service for Parents of Children with a Stoma
  Tel: 01560 322 024
  www.naspcs.co.uk
- IOA International Ostomy Association
  www.ostomyinternational.org
- Gay Ostomates Website
  e-mail info@gayostomates.org
  www.gayostomates.org

Support Organisations for medical conditions...

- Macmillan Cancer Support
  Tel: Switchboard 0207 840 7840
  Freephone:
  CancerLine: 0808 808 2020
  YouthLine: 0808 808 0800
  www.macmillan.org.uk
- Cancerbackup
  Freephone: 0808 800 1234
  www.cancerbackup.org.uk
- National Association for Colitis and Crohn's disease
  Tel: 0845 130 2233
  www.nacc.org.uk
- IBS Network
  (Irritable bowel syndrome)
  Tel: 0114 272 3253
  www.ibsnetwork.org.uk
- Incontact
  (Incontinence & Diverticular disease)
  Tel: 0870 770 3246
  Web: www.incontact.org
- National Key Scheme - Colostomates are entitled to a key which will open 7,000 locked toilets around the UK. Some local councils will provide this key free or for a small charge.

  Alternatively write to:
  RADAR
  12 City Forum
  250 City Road
  London EC1V 8AF

  Include a statement confirming you have a colostomy/disability. Enclose a cheque for £3.50 for the key and a further £10.25 if you also require the guide which lists all the NKS toilets throughout the UK.

  Keys and Guides can also be purchased on line at: www radar-shop.org.uk