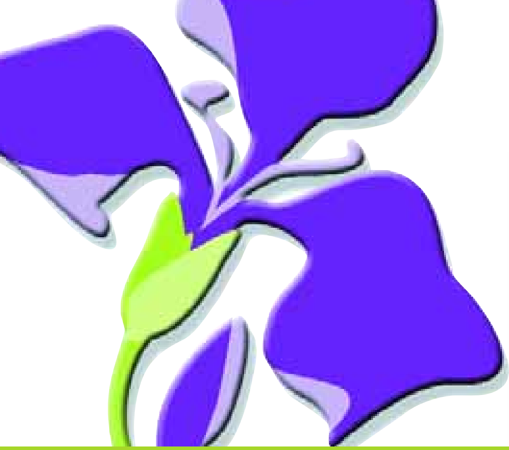

colostomy association

Tidings

Spring 2008 Issue 9

Dedicated to Colostomates and their Carers

Join us for...our next conference - Reading University

inside...

Stoma Care Professionals write about...

- rectal discharge
- how to prevent leakage

Colostomates share their experiences

plus...all our regular features

Exciting times...Moving forward again

A message from the Chairman of the Trustees...

My colostomy was formed when I was diagnosed with bowel cancer at the age of forty-six. In those dark days when I was undergoing major surgery, chemo and radiotherapy I never thought that I would live to be fifty, let alone see my two eldest daughters married and have their first babies! Now ten years later I have become a granny for the second time in three months. Orla Lily and her cousin Michael are my absolute pride and joy. My daughter, Jo, very conveniently, lives in Reading, so I can tie in the trustees' meetings with cuddles with my new grandson!

It is remarkable what a new lease of life colostomates can have after cancer and bowel disease, though I think that most of us would agree that the first year is the toughest. This is where the support of other ostomates and the Colostomy Association can be invaluable.

What a lot of exciting things are happening for the CA. Ray has been working very hard not only in organising head office's move to new premises but also pulling together the next National Conference which will be held at Reading University in September. We are planning a programme of speakers for the day and hope you will make a date to come and meet us and celebrate being colostomates!

We are so proud of Tidings. The editorial team receive many letters to say how much you enjoy our magazine full of informative and heart-warming articles. Thanks to your fund raising and donations we are now able to offer Rosemary Brierley, our editor, an honorarium for her hard work. Jane Wood, our design and production manager, is responsible for the quality feel of the magazine and the excellent graphics. We have invited Jane to be a consultant to the CA and join our trustees' meetings.

By the time you read this, I will be bionic, having had a complete knee replacement! I have a great incentive to get fit as soon as possible to make the trips to Reading, for the CA and to see Michael and Orla!

Best wishes to you all,

Sue

Sue Hatton
Chairman of the Trustees

A message from Head Office...

We are on the move...The Head Office of the Colostomy Association is in the process of moving from Station Road to London Court, which is also in Reading. This change of location was necessary due to the termination of the Station Road lease and a need to find alternative accommodation which was still affordable to us. I would like to thank Macmillan Cancer Support for their assistance over the last two years which enabled us to remain at Station Road whilst setting up the new charity.

It has certainly been a busy start to the year with a major revamp of our website just about to go live, the office move and the ongoing discussions with both the Department of Health and the Scottish Government (please see the article in this edition for an update). We are also already in to the "Open Day" season and we have received a huge number of invitations for our volunteers to attend these events. Some of the events are mentioned later in this edition but you can find a full list on our website.

Also within this issue you will find details of our 2008 National Conference which is going to be held at Reading University in September. This promises to be an exciting event with a whole host of companies and presenters already expressing an interest in attending.

To ensure that we meet the guidelines laid down by the Charities Commission, we need to formally advise everybody who is registered on our database that they are considered to be "non-voting" members of the Colostomy Association. This effectively means that the trustees of the association have the responsibility for making decisions on the day to day running of the charity along with planning for the future.

Ray Goddard
Office Manager, Treasurer and Trustee

inside
this issue of Tidings

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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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Dear Readers..

I hope you will find the usual mix of articles, by both health professionals and ostomates themselves, in this issue both informative and reassuring.

Five readers tell their stories: for some their stomas are a result of life-saving surgery for cancer, others have chosen to have a stoma to improve their quality of life. One thing they all have in common is the desire to share their experiences to help others who are still coming to terms with life with a stoma.

In recent months we have had a number of requests for information about why rectal discharge, rectal pain and appliance leakage occur and how to deal with them. Colorectal and stoma care nurses provide answers to two of these questions on pages 16 and 26 and will be considering rectal pain in a forthcoming issue. We are very conscious that many ostomates reading this magazine will not suffer from these problems, but hope you will understand that we felt it important to include these articles for the minority who do. Likewise we do not want new ostomates, or those facing stoma surgery, to think that rectal discharge or leakage is inevitable – it isn't – just to be aware that it may sometimes happen and why.

Hints and tips for new ostomates proved very popular in our last issue and many of you wrote to tell us about other novel ideas to make stoma care easier. We have included these at the end of our follow-on feature of hints and tips for colostomates who irrigate.

I can't believe that it is almost two years since I began editing Tidings. During that time I have really enjoyed reading the articles you have sent in. I must admit to feeling a little envious when I heard about the places all over the world you have visited. Now it is my turn: as you read this magazine I will be at sea, beginning a six week cruise. So I'm afraid I won't be around to edit the next issue. Ernie Hulme has kindly agreed to stand in as editor.

Best wishes,

Rosemary

Rosemary Brierley
Editor

Submissions: If you have a story, 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: 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.

Supply of digital images: When supplying digital images for inclusion in Tidings please try to observe some or all of the following criteria;

- Images should be in RGB mode
- Images should not be less than 2480 pixels x 1772 pixels at 300 pixels per inch (equal to 21cm x 15cm).
- File sizes not less than 10Mbytes uncompressed
- Images compressed in JPEG format.
- For scanned images please set at 300 ppi in RGB mode and scan original @100%

If you need assistance please call Jane or Mike on 0118 983 6226

The Colostomy Association National Conference 2008

Following the success of our first National Conference, held in Sutton Coldfield last September, the Trustees have decided to change the format of future events. Last year's event was sponsored by our good friends at Salts Healthcare and included some very interesting presentations about hernias, Macmillan Cancer Support and the Department of Health Consultations.

Although this was very successful, we felt that our members would want to have a wider range of products to see and more time to visit the stands. We are, therefore, pleased to announce that the 2008 National Conference will be held at Reading University on Thursday 11th September. Planning is at an early stage but already fifteen manufacturers and supply companies have expressed a wish to attend. We are also in liaison with a number of potential presenters for the day and we hope to be able to include a fashion show sponsored by one of the large high street stores.

Further information along with a booking form will appear in our Summer Tidings. There is limited hotel accommodation on site and we will provide details of this along with other local hotels.

Please mark the date in your diary and look out for more information in the Summer Tidings or on our website www.colostomyassociation.org.uk.

Tidings

Dedicated to Colostomates and their Carers

Courtesy of Reading University

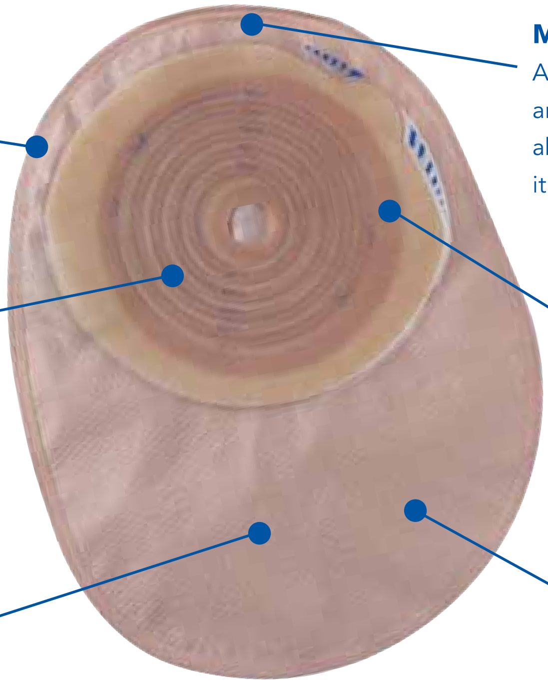
Conference Venue
Reading University

The Forbury Gardens

The Oracle Shopping Centre

The Old Town Hall

Around Reading...



Volunteer profile... Yvonne Penfold

Yvonne pictured with her husband

The consultant looked sternly at me across his desk. 'You have a malignant tumour in the bowel,' he said. 'I'm afraid all I can offer you is acceptance. We'll try to avoid a colostomy, but I can't promise.'

He said he would put me on the list for surgery and dismissed me, calling me by the wrong name. Relief swept over me. Of course it was a mistake, he had the wrong file, everything was alright after all. But he didn't have the wrong file: he was just careless about names. I left the hospital in a daze. As we all know, cancer is only for other people.

I went through all the stages that everyone does when confronted with such a verdict. 'Why me? I have led a good life. It isn't fair.'- but where is it written that life has to be fair?

Gradually panic subsided enough for me to take stock of the situation. I realised I must put my house in order. I reviewed my will, stocked up the freezer and turned out the cupboards. Two weeks later, three days before Christmas, I entered hospital.

It was necessary to be both starved and purged for two days in preparation for the surgery, a process over which I shall draw a veil. At least they didn't give me an enema. On the third day I was wheeled, shaking, to the operating theatre.

I woke that evening, vaguely aware of a choir singing carols nearby. Had I entered the Pearly Gates I wondered? Then I remembered that this was Christmas Eve. Gingerly I explored my abdomen. Glory be – no bag. I had avoided the dreaded colostomy and I felt jubilant.

They told me later that the operation took four hours. At the end of it the surgeon phoned my husband to tell him how delighted he was with the way things had gone. The tumour was new, small and mobile as he had thought. He had managed to completely remove it and I was a very lucky woman.

After ten days I returned home, a good deal slimmer and distinctly fragile but thankful to be rid of the cancer. Now all I had to do was get well and hope for the best. Something told me that might be more difficult than it seemed.

Recovery was slow and painful but by the end of six weeks I felt I had done pretty well. Now came my post-op hospital appointment. I saw a very young doctor who gave me a couple of prods and told me cheerfully to come again in six months time. Casually I said, 'I won't need radiotherapy then?'
'Oh,' he said. 'I haven't looked at the histology report. Uuummm I'll go and ask someone else to see you.'
After some delay a more senior man arrived. He held my hand and called me his dear and I realised I could be in trouble. He would write to me about possible radiotherapy.

Several weeks went by and I started to ask questions of my GP. She phoned to say she now had the lab report and would like to see me the following Thursday. This was Monday. I said I would like to know now, please. So she blandly told me the news was not good. Despite the surgeon's insistence that he had "got it all" the cancer was Grade C extending through the colon wall and into the lymph nodes. 'But don't worry,' she said. 'You're not going to die in the next three months.' At my appointment on the Thursday she drew me a chart of the state of my colon and told me the chance of survival for five years – 40% at the most.

So in April 1994 I began five weeks of daily radiotherapy. Apparently I had a very heavy dose, so much that I must not have any more on my abdomen, no matter what happens. By the end of the course I felt very poorly indeed and the effect of the therapy on my colon was dire. The surgeon who saw me every few weeks that summer could only say, 'Soldier on, dear. It may get better.' It didn't of course and after an indescribable time of pain, loss of control and being unable to leave the house for more than an hour or two, it was finally decided to give me a colostomy. At one time I had dreaded such a thing but now welcomed the decision, feeling it was the only way to get my life back. With perfect timing the operation was performed on my sixty-fourth birthday.

It took several weeks to get used to my colostomy. I learned by trial and error the kind of food I should avoid. Sadly I found that a couple of glasses of wine can have a dire effect, so I only drink wine when at home. Finding the most suitable bag was another problem. I tried about ten before I found one that didn't irritate my skin or come unstuck. A colostomy bag coming adrift must rank pretty high on the scale of embarrassing moments. My sense of humour has been sorely tried at times – it's all part of the learning process.

A few months after the colostomy operation I was able to do practically everything I could before. No longer need I hover near a loo. I was FREE and for most of the time I could forget I had a stoma. Of course, I would very much rather not have it, but I accept that the operation is a lifesaver.

Another autumn and winter passed and I grew used to my new lifestyle. I felt more or less back on track, though the prospect of a recurrence was always on my shoulder. By March the following year I began to feel uneasy about the discomfort I was feeling. My GP was adamant that after all that radiotherapy there could not be a return of the cancer. In desperation I moved to another practice and made an appointment to see a different doctor. A couple of visits on and the new GP asked if he could take a biopsy. 'Be my guest,' I said. And so it turned out that two weeks later, on the eve of flying to Denmark for a brief holiday, I received the dreaded phone call. I had been right. The cancer was now in my vagina and I must cancel plans for the rest of the summer.

I saw a gynaecology consultant the very next day, en route to the airport for the trip to Denmark and he gave me the option of having very radical surgery – 'just about worth it but no more' or taking the chance of treatment in the oncology centre. A couple of weeks later I was in hospital again. I spent three or four days in a lead-lined room without a window or visitors as, having iridium wires planted into the vaginal tumour, I was dangerous to be near!

Compared with the horrors of the previous surgery, this procedure was a "doddle". The oncologist said he would not know for at least two years if it had been successful; the chances of success were again 40/60. He omitted to mention that as time went by the burning would get more and more painful. But eventually it subsided more or less and once again I have had to hold on to the thought that it is the price I have to pay for being here.

Ten years or so passed and the oncologist decided that the time had come when he could promote me to annual check-ups for the first time. To celebrate my recovery we flew round the world spending five weeks in New Zealand.

In 1997 Yvonne was asked by her stoma care nurse to visit patients who were about to have, or had recently had, a colostomy. She is now a volunteer for the Colostomy Association.

In the News...

Cancer Charities Merge

Macmillan Cancer Support and Cancerbackup are delighted to announce that they have agreed to merge.
The merger will further the aims of both charities to ensure that, across the UK, everyone affected by cancer will get faster and enhanced access to high-quality information at every stage of their cancer journey.

Both Macmillan and Cancerbackup are dedicated to supporting people affected by cancer. Macmillan develops and provides a wide range of medical, practical, emotional and financial services, including the distribution of information. Cancerbackup is the specialist cancer information charity, recognised as the UK's leading source of high-quality information on every cancer.

The merger will enable Cancerbackup's existing services to be expanded and enhanced as they join with Macmillan's full range of services, to the benefit of people affected by cancer, their families and carers.

Information services will be delivered under the sub-brand Macmillan Cancerbackup and will include:

- improved telephone helpline support through an enhanced direct cancer information service with access to cancer information nurses, nutritionists, financial and other experts
- enhanced information on the Macmillan Cancerbackup website and in booklet and new formats, based on need
- accessible, approachable information and support centres through the UK, not only providing high quality support but also acting as central points for outreach services.

The Colostomy Association would like to wish Macmillan and Cancerbackup every success in this new venture. C.A. has had close links with Macmillan since1972 when Macmillan Cancer Relief took over the funding of our predecessor the Colostomy Welfare Group, which subsequently became the British Colostomy Association. We would, therefore, like to take this opportunity of expressing our gratitude to Macmillan for providing the necessary finance for us to continue to support colostomates for more than thirty years.

A week in Cornwall for Colostomy Association raffle winner...

Jean Wilson was the lucky winner of first prize in the raffle held in November 2006 to celebrate the Colostomy Association's first year. The prize was a week in Cornwall in the village of Constantine staying in a beautiful converted grain mill overlooking the Helford River. The holiday was donated by Sue Hatton, Chairman of the Trustees, and her husband, Neil.

Jean wrote to say:
'We had a wonderful trip. I went with my husband and two daughters. The view from the cottage was absolutely stunning. Sue said they first saw their cottage from a boat whilst on holiday and they fell in love with it – I can understand why. There was so much to do and see – in fact it was a holiday to remember for all of us. Thank you to Sue and Neil for the lovely Cornish cream tea waiting for us when we arrived. They made us so welcome.'

Grant for research into "high output" stomas...

The Stoma Care/Colorectal Department at the John Radcliffe Hospital, Oxford has been awarded the Opus Healthcare Bursary, a research grant of £5,000.

The Opus Healthcare Bursary is an annual award presented to Stoma Care or Colorectal Nurses to facilitate innovative research aimed at increasing the understanding of a particular aspect of stoma care, which will hopefully lead to an improvement in the quality of life for people living with a stoma.

As a team, the Stoma Care / Colorectal nurses at the John Radcliffe Hospital will conduct research to determine whether there are contributory factors involved when a patient, following surgery to create a stoma, goes into "high output", post operatively.

Results will be presented at the WCET UK Conference in September 2008.

Roy Tansley wins again

Roy Tansley had a colostomy formed in June 2006 followed by five weeks of radio/chemotherapy because of bowel cancer. In Nov 2006, the day before his operation to remove his lower bowel, rectum and anus, Roy won a crown green bowling tournament and donated his £20 prize money to CA. For six months from Jan to June 2007 he had chemotherapy. However, he still managed to play bowls for most of the season. His team gained promotion and Roy himself won another competition and again sent us his £20 winnings.

Roy says, 'So you see, fellow colostomates, there is life after radio/chemotherapy and two operations. I am now sixty-one years of age and feeling remarkably well and looking forward to the new bowling season in April 2008.'

From Abroad...
Decision on eligibility to the French Health Service

Immigrants arriving after the 23rd November 2007 will be unable to join the French Health Service (CMU) unless they are either working in France or over retirement age. Those resident in France before that date who are neither working nor over retirement age will nevertheless be able to remain in the CMU.

hints and tips...on irrigation

We continue the feature we began in the last issue with suggestions to help ostomates who irrigate.

For those readers who are unfamiliar with this technique, irrigation is a method of colostomy management which involves using specialist equipment to introduce water into the bowel via the stoma. The water then causes muscular contractions within the bowel which in turn cause expulsion of its contents.

Before considering irrigation it is essential to check with your surgeon that this form of colostomy control 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.

For best results, try to irrigate at regular intervals.

Some people find that a hot drink before they irrigate helps to stimulate the colon.

Water should be neither too hot nor too cold. 37°C to 38°C is considered to be the appropriate temperature range, but some people find 39°C to be better. 40°C is too hot. Remember the water is cooling all the time you are running it in, so it is preferable to start at the top of the range particularly if you take a long time.

Introducing the water

Provided the reservoir is not more than 15cm (6 ins.) above shoulder height it may not be necessary to restrict the rate of flow. The colon is capable of controlling the flow itself and even of pushing water back into the reservoir. People who use an irrigation pump typically introduce the water in half the time without any ill effects.

To make it easier for the water to enter the colon, keep your upper body straight rather than hunched over.

Many people consider that squatting on the WC seat is not the best position in which to conduct irrigation and instead sit rather higher on a stool. This is not always convenient if the room is small as a stool either has to take up an unacceptable amount of space, or be moved in and out as needed. The problem can be solved by buying a folding shower seat, and fixing it to the wall at the preferred height.

Some people prefer to stand or to lie in the bath to let the water in.

Irrigation works best if you are relaxed. If you do not have much time or are uptight about anything, the water is often reluctant to go in.

If you experience discomfort while introducing the water, stop the flow and massage the abdomen. Some people find that they don't need to stop the flow if they pull in their tummy, using the lower abdominal muscles, a few times to "jiggle" the colon. This relieves the discomfort and allows the water to continue to flow in smoothly.

If when the reservoir is empty the water in the tube falls much below chest level this indicates that the cone is not sealing properly. You may not be introducing as much water as you thought and need to apply more pressure to the cone to seal it.

When you have run the desired amount of water into your stoma, hold the cone in place for another twenty seconds or so, to allow the pressure to equalise. If you remove it too soon some of the water you have already put in will just gush out without serving any useful purpose.

When you do remove the cone, make sure you keep the upper edge of the sleeve well above the level of the stoma, or you may find that what emerges comes over the top.

After irrigating

Keep the sleeve in place until you are sure evacuation is complete. The sleeve can be rolled up so you can walk round until you are confident that there will be no further discharge from your stoma.

Have a pair of scissors handy to cut about 30cm off the end of the sleeve where it has been in the toilet. It is then dry and fairly clean which avoids wet or soiled underwear, which sometimes happens if you roll up the whole sleeve.

Irrigators abroad

- Water

If the water is fit to drink it is suitable for irrigation.

If the water supply is suspect, then there are three options:
Boil a kettle in the evening and leave it to cool overnight. This provided the cold water and another kettleful boiled in the morning provides the hot to mix with it to obtain the correct temperature.
Use water sterilization tablets.
Use bottled water, making sure the seal is intact before the bottle is opened.

- Hanging up your reservoir

We have received a variety of suggestions of what to take with you to hang up the water bag.
A wire coat hanger (bent into an S shape) or a butcher's hook (obtainable from IKEA) can be hooked over a shower rail.
Velcro straps can also be fastened round a shower rail.
A vacuum hook can be stuck to a smooth surface i.e. tiles, but always use two because they can release without warning.
Remember - if you can – to take the hook/hanger with you - when you leave!

- Don't get dehydrated!

If you find when you go to a hot country that your irrigation doesn't work as well as at home, it could be because you are becoming dehydrated, so keep a water bottle with you and aim to drink at least the recommended two litres a day.

Remember that when you feel thirsty you are already dehydrated. It is better to drink water at room temperature than ice cold because warmer water is absorbed more quickly and cold water quenches your thirst before you are rehydrated.

If you wake up during the night feeling thirsty, don't just take a sip, drink half a glass.

But remember...

Everyone is different in the way their body responds to irrigation. The ideas above are for you to try out and you may find some of them useful.

A leaflet entitled "An introduction to Irrigation" is available from CA 0800 328 4257.

hints and tips...
our readers comment

Several readers wrote or e-mailed to comment about the hints and tips which appeared in the last issue and to add more suggestions of their own.

Shaving

My recommendation has always been a BIC Sensitive disposable razor which is, I suspect, cheaper and probably more readily available than a Ladyshave. However, now that washable electric shavers are available that is my own first choice. I only held back from it previously because of the problem I would have if the stoma misbehaved while shaving!

Pancaking

Covering the filter with a sticky patch is intended to retain some air in the bag, not to prevent a vacuum forming, which is impossible. Interestingly, some manufacturers provide four-position patches to adjust the area of the air outlet from zero to maximum.

Drying around the stoma

My wife suggested using a small battery powered hand fan to dry the skin when changing the bag and this works well. It is much more convenient than using something like a hair dryer, especially when away from home.

Car seat belts

Many of us find that the seat belt can be uncomfortable not only because it exerts pressure in just the wrong place but because it is unacceptably tight. An effective solution is to fix a clip to the belt. This can be used to hold the belt a little less tightly. You set the clips at the tension that is comfortable for you, but does not interfere in any way with the proper purpose of the belt – namely your safety. The clips are sold in pairs at motor accessory shops and many garages. They are also available on line from www.care4car.com (click on Car Accessories).

Your questions...
about travel and holidays...answered

We receive many queries via the internet and on our helpline every week. At this time of year many of these calls are from ostomates planning a trip abroad or seeking holiday insurance.

I need your help! We are going to Australia to see our new grandson. I have Secondary Progressive Multiple Sclerosis and I am wheelchair bound. As I am fully catheterised and have a colostomy, I will need to take a number of items i.e. leg bags, colostomy pouches, liquid gels, plus all my usual medication. My husband, who is my full time carer, will be with me. My question is will I be able to take all my bags and medication on board as hand luggage. I would feel very uncomfortable if I had to put them in the hold. If our baggage did go missing what would I do?

A. First check with your airline and confirm your hand baggage allowance. Then check the weight of all the items that you will need for your stay, remembering that you will need at least one and a half to two times the number of colostomy pouches you would normally use to allow for tummy upsets etc. If this is well above the weight limit, you have two choices. You can split it between your hand baggage and that of your husband or contact the airline and request a special medical allowance.

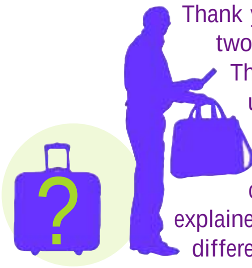
You could also contact your supplier (or manufacturer) and see if they will send some supplies on ahead to your son's address.

You may have to allow the liquid gel to go into the hold – security do not like any liquid container larger than 100ml. However, check with the airline close to your departure date as security rules may change.

I agree that your medical supplies should not be in your general luggage that is placed in the hold - to lose those would indeed create problems. It is advisable always to take with you a list of codes and names of your medical items just in case you should need to obtain further supplies. You could telephone your supplier in England to see if they have contacts in Australia - or better still if they could send out replacement items. Holiday Insurance should cover the cost if such a thing should be needed.

In a previous issue of Tidings there was an article about travel insurance written by a man - an insurance broker, I think – who was himself a colostomate and he had reasonable annual travel insurance available. I wonder if you could send me his contact details if you still have them. My husband and I are going on a cruise and I want to arrange travel insurance. To be honest over the past three years I have travelled on ordinary insurance stating my disability in advance but this would be so much better.

A. The insurance you mention is the Colostomy Association Travel Insurance Policy (CATIP). It is available through our website www.colostomyassociation.org.uk If you click “travel insurance” (left hand side of home page) you will be taken direct to receive a quote.
We also have a list of other insurance companies that have been recommended by ostomates.



Thank you for sending me two travel certificates. They should be very useful at airport check-in as the fact I have a colostomy is explained in so many different languages. However, when I took them for my GP to sign I was informed by the receptionist that this would cost £10 for each form. As I am a senior citizen I thought this was quite extortionate I would appreciate your comments please.

A. You could try waiting until you have an appointment to see the doctor about some other matter and ask him to sign it while you are in the consulting room. Signing the form will then not involve any other member of the practice staff finding your notes as the doctor will have them there in front of him and he may be willing to waive his fee. We can’t guarantee it though, so an alternative might be to ask your stoma care nurse if she would be able to sign it.

I am going on a cruise later this year. How will I dispose of my bags whilst I am on board?

A. Empty in the usual way and put the soiled pouch inside a disposal bag and leave it in the bin in the bathroom which will be emptied at least once a day. Even flushable appliances should never be put down the W.C. on a ship or an aircraft as they will block the system.

Remember

If you have any queries about holidays and travel or would like:

- a copy of the leaflet, Travel Advice
- a Travel Certificate
- our list of insurance companies

contact CA by phoning our helpline:
0800 3284257 or
e-mail:
cass@colostomyassociation.org.uk

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Vietnam...
Biking challenge

Evan Robinson at a fundraising event for Macmillan in green T-shirt, pink wig and Dame Edna Everidge type glasses

Mr Chung, my Vietnamese host, spoke no English. But the look on his face told me he could smell my leaking pouch. As I sat on the settee in his house in Hanoi, North Vietnam, I looked down and saw a brown stain spreading over my light khaki trousers. How I wished that floor of polished hardwood would open up and swallow me.

Did Mr Chung understand what was happening? I had no idea except that he beckoned me from his living room and showed me the way to the toilet. The pouch by now had come away completely and, even worse, I had no spare. I returned to my host's living room, made apologetic gestures, and bid good bye.

He followed me out of the house and flagged down one of the ubiquitous motor cycle taxis that abound in Hanoi. Mr Chung gave instructions in Vietnamese to the rider as I climbed on the pillion. Whatever he said I found myself being whisked away at breakneck speed through the heaving Hanoi traffic. I glanced backwards just in time to see Mr Chung nodding and waving. Mr Chung, I concluded, was not stupid. He understood what had happened.

I was very relieved to get back to my hotel room on the other side of the city. The motorcycle rider asked for no money. The understanding Mr Chung had evidently sorted that too!

Any ostomate reading this might ask the question: why was I not carrying a spare pouch with me? I think the best way to answer that is to start my story from the beginning, one year before.

The invitation in October 2006 to join the first Vietnam Biking Challenge for Macmillan Cancer Support was an offer I could not refuse. It would, according to Macmillan, be one of their toughest challenges yet. Participants would have to ride pedal cycles across nearly 500 miles of mountains in Northern Vietnam. We would venture into areas never seen by tourists. Hard to believe but plausible when you think that Vietnam has only been open for tourism in the last ten years. And then tourists have mainly visited cities like Hanoi and Ho Chi Minh (previously and still called by many, Saigon). Northern Vietnam was by all accounts remote and unexplored. Not even the American war extended that far up. It was a once-in-a-life-time opportunity!

> But I have a colostomy. Could I look after it in such primitive conditions? Well, I reasoned, I've done similar things before so I should have learned all the lessons there were to learn…

But first there was the matter of fundraising. Macmillan required a minimum of £3000. I had two methods. My main method was to go from door to door in my neighbourhood asking for sponsorship. The other and more attractive one was put collection boxes in local pubs. It meant that the boxes had to be checked regularly and collected when they were full. And since I can't go into a pub without having a drink…

One pub decided to hold a karaoke evening to raise money especially for my appeal. The fundraising party was in full swing and I was dressed, as you do, in a green Macmillan T-shirt, pink wig and Dame Edna Everidge type glasses. Suddenly my T-shirt is pulled up and a camera flashes. In the middle of a crowded pub the last thing I expected was that someone would unwittingly reveal my stoma to the world. I was glad I'd irrigated before the party so that I only needed a stoma cap.

As the months went by I prepared for the Vietnam Challenge with more fundraising and training. Then as the time grew near I thought more about what to take with me for my colostomy. I planned to irrigate every second night so that I would only have to use stoma caps like the one in the photo. I would take extra supplies of pouches in case I had a stomach upset: a very real possibility in Vietnam. But because I had decided to take my own bike my baggage weight was severely limited by the airline. Everything, including my stoma supplies, had to be kept to the absolute minimum.

The first night of the Vietnam Biking Challenge was in remote village west of Hanoi. We slept in a primitive hut on rush mats. There was a hut for the men and another for the ladies. However, I was more interested in the toilet facilities: they were good with flush toilets and even a hook to hang up my water bag. But there was no lock on the door so I rose early to ensure privacy. It was still dark and as there was no power; I needed a torch to see what I was doing. The tropical heat had warmed the bottled water to near body temperature. Irrigation went well and I quietly made my way back to the men's hut while everyone was still asleep.

Two days later I needed to irrigate and set about organising my items. But where was my water bag and tube? I frantically searched all my bags. The water bag was not there and without it I couldn't irrigate. I must have left it behind in that dark toilet on the first night. How could I have been so careless? I found a tour guide and explained my predicament. Could he contact the village where we stayed and get it sent on? His answer was no; this is remote Vietnam, not Milton Keynes. I went back to my room and sat on my bed, head in hands. What could I do?

Amongst my belongings was my platypus. I use it for carrying drinking water on my back. It consists of a 2 litre plastic bag and a tube and mouth piece. Could I adapt it? There was no cone to suit my stoma, just the open end of the tube if I removed the mouth piece. I tied some string to the bag and filled it with drinking water. Suspending the bag I tried inserting the tube in my stoma. It leaked and water went everywhere except into the stoma. I stared at my belongings again. There was a first aid kit. I wrapped some sticking plasters around the end of the platypus tube to make it bigger and tried again. This time some of water went into my stoma. More plasters improved it. It was difficult and messy but working. I had improvised a temporary irrigation kit. For the remainder of the biking challenge my platypus would have a new job.

The Vietnam Biking Challenge was incredibly hard but immensely rewarding in terms of the camaraderie and sense of achievement. Adding the hills together, we had climbed over 33,000 feet, higher than Mount Everest, in temperatures of 100 degrees and almost 100% humidity. Eventually we reached our goal high in the Northern Mountains near China. Forty-nine ordinary people had accomplished something truly remarkable. We were exhausted and dehydrated but elated. Then we remembered why we were there: to help people living with cancer. Between us we had raised £200,000. Many of us had experience of cancer either directly or indirectly through friends or relatives. My colostomy was because of cancer. Emotions ran high and there were tears.

After a day in the North Vietnamese town of Sa Pa we took an overnight sleeper train back to Hanoi. For most, their Vietnam experience was over and there were emotional goodbyes to those returning to UK. But I and a few others still had a few days to enjoy.
My bike, however, after its 500 mile trek, was badly in need of a service. Our local tour guide recommended a mechanic, a certain Mr Chung who owned a bicycle shop on the other side of town. The hotel receptionist rang Mr Chung on my behalf and he turned up an hour later to collect my bike. He said, via the receptionist, that it would be ready the next day. I enjoyed a relaxing day's sightseeing and in the evening irrigated my colostomy with the makeshift kit.

The following morning those of us still in Vietnam agreed to meet up that evening for a slap up meal to celebrate. I ordered an expensive meal by Vietnamese standards (the equivalent of £5 in the UK). It was a spicy stew with various meats and vegetables served in a metal pot on an alcohol burner. The waitress told me to wait a few minutes before starting. But I was hungry and it smelt delicious. Practising with my chop sticks (and perhaps showing off) I selected morsels of meat and washed it down with cold beer. A fellow biker reminded me of what the waitress said about waiting a few minutes before eating. But the stew was bubbling away nicely and it tasted so good I took some more. The other meals arrived and all tucked in. It was a great evening.
After a good night's sleep I showered. My colostomy was clean and I felt good. I put on a stoma cap and went down for breakfast. As a precaution, as always, I put a spare pouch in my pocket, just in case. I took a taxi across town to Mr Chung's shop. On the way I felt a tummy gripe. It wasn't much but when I checked my stoma there was a slight discharge. I paid the taxi and found a quiet corner. The capacity of the cap was minimal and I decided to use the spare pouch.

All was well as Mr Chung invited me into his shop. Although we spoke different languages we both loved bikes and formed an instant friendship. Mr Chung had taken part in many biking competitions and as he proudly showed me his trophies my stomach felt increasingly uncomfortable. He offered me Chinese tea which I felt obliged to accept. By the time he got around to showing me my bike I knew I was in trouble. He offered me a seat which I gladly accepted. Suddenly my stoma discharged heavily. And this, reader, is where you came in.

Back in my hotel I undressed and stood in the shower. When I was clean I dried myself and, still in the shower cubicle, applied another pouch. I lay on the bed and in moments was asleep. I awoke to a feeling of wetness and sat up quickly with my hand over the stoma but it was too late. How could I possibly explain what had happened? However, it seems that tourists with the "back door trots" are not unheard of and the hotel management took it in their stride. I had to pay $20 (£10) to have the mattress specially cleaned. It wasn't the cost I felt as much as the embarrassment. Should ostomates carry extra protection for hotel beds when on holiday?
I thought back to what I had done to get this tummy upset. It must have been that celebration meal where, due to my greed, I didn't follow the waitress's advice and ensure my food was properly cooked before eating.

Every time I go away from home I try to learn from my mistakes. And I always seem to make a whole load of new ones! Perhaps one day I will get it right...

Evan Robinson

How to... prevent leakages

Pat Black MSc, RGN, RCNT, FETC, DipN, FPA Cert
Lead Nurse for Stoma and Colorectal Services
The Hillingdon Hospital NHS Trust
Uxbridge Middlesex.

When stoma appliances leak it can be upsetting and socially embarrassing. So how can we stop this from happening?

Why appliances leak

Appliances appear to leak more often once you have left the hospital and are back at home recovering from surgery. And here is the first answer. You are tired and exhausted and the last thing you want to do is change the appliance. Often not remembering part of the procedure accounts for leakage and sore skin. The answer is to take your time and have all your equipment ready and in a convenient place, and perhaps use the picture chart of changing an appliance for guidance.

Begin putting on your pouch by positioning the adhesive flange on the skin immediately below your stoma.

Press the flange from centre to edge with your fingers to ensure it is securely in place. Continue around the stoma until you are certain the flange fits snugly and securely.

Sometime leakages occur because the size of the stoma has shrunk after surgery and the aperture of the appliance is too big. Re-measuring of the stoma may solve the problem. You can either do this with the help of the stoma care nurse or on your own using the guide in the box of appliances.

Use the stoma guide to check the starter hole of the adhesive flange. If your stoma is uneven or oval, adjust the starter hole with small sharp scissors. Remember it is important that the hole fits your stoma snugly without applying any pressure. This prevents redness in the immediate area around the stoma.

Perhaps if you have been very ill before surgery and are now putting on weight the change in body shape may cause the appliance to leak. Likewise loss of weight after surgery and not regaining it as time goes by may also cause appliance leakage. In both these cases your stoma care nurse will be able to advise you as to why the leakage occurs and help with choosing a suitable appliance to accommodate the change in your body shape.

Chemo or radiotherapy after stoma surgery may add to appliance leakage problems and cause sore skin around the stoma. With these treatments it is not unusual to have diarrhoea and patients can feel quite debilitated. At this time, a two-piece appliance is often useful as the appliance can be changed as often as needed without disturbing the flange.

Stoma care accessories

Paste, washers and flange extenders all have their place in stoma care and may be helpful for those who have frequent leaks allowing them to remain on the appliance they prefer.

The role of pastes and washers is to act as fillers in gullies and dips, to even out the skin surface making a flat surface to apply the pouch.

Paste comes in a tube and other than one product, produced by Pelican, they all have an alcohol base to help with drying. The disadvantage with anything that is alcohol based is that when it is used on sore or broken peristomal skin it will sting. Paste is also difficult to apply and leaves residue on skin and fingers.

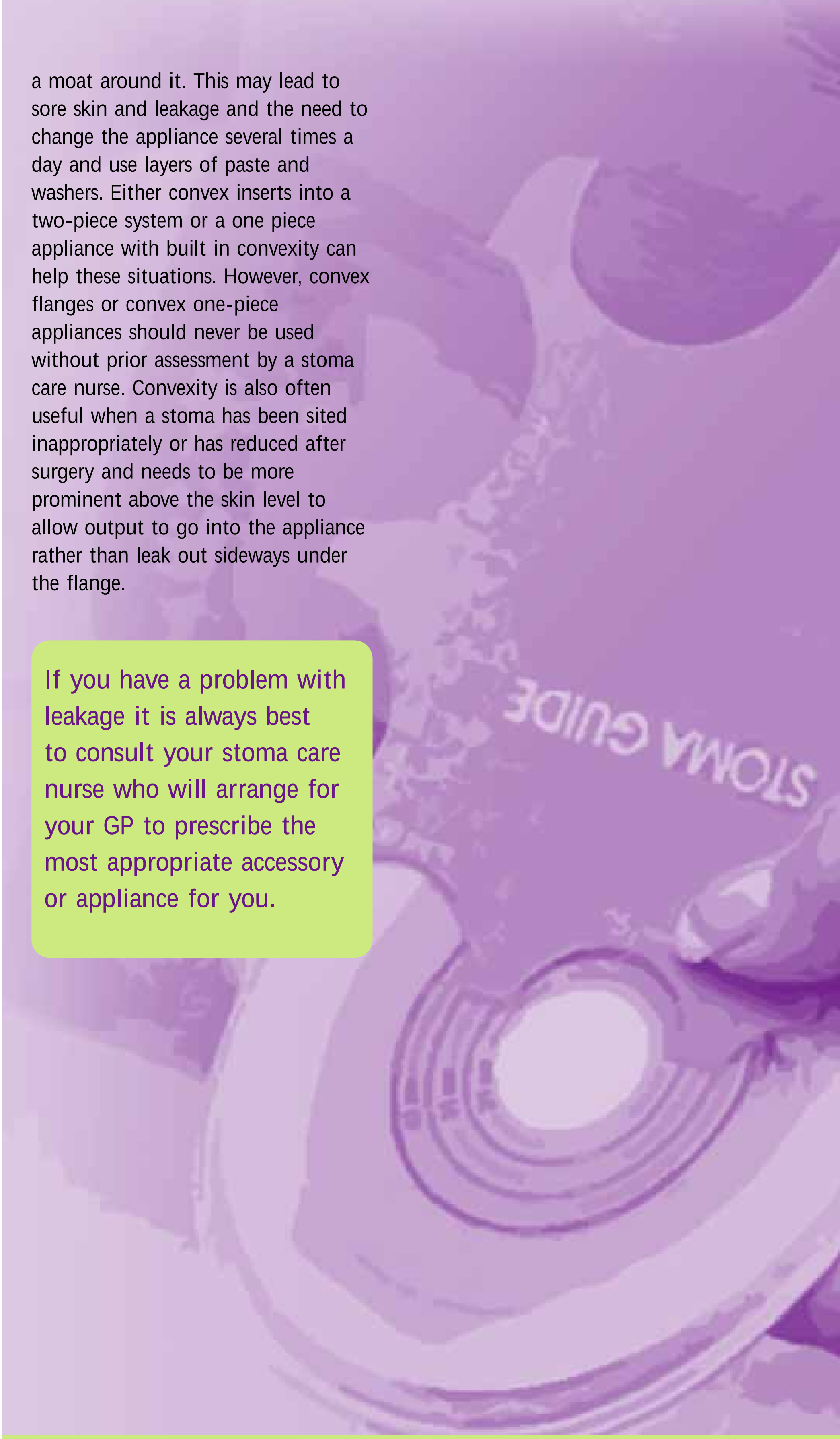
Washers are paste in solid form. These rings can be moulded into shape to provide a secure seal around the stoma.

Flange extenders increase the sticky area of the flange for attachment to the peristomal skin which can be useful especially when there is a parastomal hernia. The extenders can be made of zinc oxide tape or hydrocolloid material like the flanges on appliances. Hydrocolloid makes a better interface with the skin, whereas zinc oxide tape may strip away delicate skin layers.

Convexity

Convex flanges have a place in stoma care and are often used to correct a leakage problem. Colostomates may have had their stoma created many years previously and, along with age and body changes, the stoma may have receded into fat folds, become stenosed, retracted, flush or developed a moat around it. This may lead to sore skin and leakage and the need to change the appliance several times a day and use layers of paste and washers. Either convex inserts into a two-piece system or a one piece appliance with built in convexity can help these situations. However, convex flanges or convex one-piece appliances should never be used without prior assessment by a stoma care nurse. Convexity is also often useful when a stoma has been sited inappropriately or has reduced after surgery and needs to be more prominent above the skin level to allow output to go into the appliance rather than leak out sideways under the flange.

If you have a problem with leakage it is always best to consult your stoma care nurse who will arrange for your GP to prescribe the most appropriate accessory or appliance for you.



The illustrations above are taken from “Colostomy Care at home” which is a step by step pictorial guide of how to change a colostomy pouch. This leaflet can be obtained from Dansac 0800 581117. A DVD entitled “How to prepare and apply a colostomy pouch” is also available.

There is light at the end of the tunnel

I am forty-five years old and have had a colostomy for the last fourteen years. In 1993 I had a nervous breakdown and was hospitalised for ten weeks; it was only then that the nurses saw the problems that I was having with my back passage. I'd had no control over it at all since I had been five months pregnant with our daughter back in 1989.

Up until getting pregnant I knew when my bowel was about to evacuate but seldom did I get to the toilet in time. My GP kept saying it was just nerves, but I knew different. It had been like this for as long as I could remember: all the "tellings off" as a teenager, my mum saying I was just lazy.

During the breakdown it came out that as a child I had been abused. I had blocked all the horrible stuff out as it had been too traumatic to remember. Over the next year things started to come back into my head like a jigsaw, I would remember part of an incident but not all of it.

Around this time my GP sent me for tests on my sphincter muscle: they said it all. The consultant told me that my sphincter muscle had been stretched beyond its elastic limit prior to puberty, which was why it wasn't working. He recommended surgery.

If he had told me before the surgery how painful it was going to be I would never, never have consented to the operation. For four weeks I could hardly walk. It was six months before the swelling had gone down enough to remove the last of the stitches and before I could properly sit and drive my car.

I had control of my bowel for about five months. It was fantastic. Then the muscle started to fail and I just went backwards. It was soul destroying. If I had not had my fantastic husband, Mel, I could not have coped. He shared everything with me: he was so pleased after the operation and said I was back to my old self and so positive for the first time in years. When we went back to see the consultant he just said I was lucky it had lasted this long. I was devastated. If he had told us it would only last twelve months if I was lucky then I would not have had the operation.

My only option now was a colostomy and to be honest I couldn't wait for the operation. I knew it would give me some sort of a life back and I felt I could not move forward until it was done. I think it was harder for my husband as he did not know what to expect. I had my operation on a Monday and came home on the Friday, the first day of my new life, and that is what it was. I have never looked back; it was the best thing that could have happened to me.

Over the first few months the stoma shrank into a set 25mm and has been the same ever since. Apart from the odd pancaking it does not affect me at all. I became a market trader for some years whilst our children grew up and then in 2001went back to full time work with Her Majesty's Coastguard as a marine surveyor. I am used to jumping from boat to boat in the middle of the sea in a dry-suit, climbing under boats ashore to do bottom inspections. I have just changed my job so that I am now in the office, on the radios as part of the emergency service that the coastguard provides 24/7 all year round. In my spare time I skipper a charter boat taking people out sightseeing or fishing.

I had a lot to cope with during 1993 to 1997 but I hung in there and now I have finally got my life back. I do not think I will ever forget why I have the colostomy and I see things on the TV that sometimes make it hard to keep my composure, but I have a wonderful husband whom I love to bits. We have been together since 1985 and have a wonderful life.

For anyone who is about to have the operation my only comment is don't let a colostomy get in the way. You can do anything if you want it bad enough. I am living proof of that.

This is the first time I have told this story to anyone except my husband and the therapist. If it helps just one person then it was worth telling.

Pearl

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Update...

on new stoma care products and services

Fittleworth is launching a new home from home emergency service offering peace of mind to ostomates travelling the globe. The World Assist Alliance (WAA) has been designed to support travellers with stoma needs by offering emergency delivery to the same level abroad as the discreet service received at home.

Many Fittleworth customers with a stoma have expressed anxiety about travelling abroad. Now the fun-seeking tourist or the serious business traveller can be secure in the knowledge that the values of discretion and quality will be maintained abroad as at home.

Fittleworth has currently identified eleven partners in Austria, Belgium, France, Germany, Holland, Portugal, Spain, Switzerland, Australia, New Zealand and the United States with more to follow. Each partner company has made a commitment to help member travellers when visiting their country by providing rapid delivery of goods, offering advice or arranging for a visit from a local specialist nurse.

Membership of the WAA will be offered to customers of Fittleworth's Home Delivery Service. No charge will be levied for using the service and there will be no need for a prescription to cover the emergency goods. The cost will be borne by the WAA network members: for UK customers the NHS will not be charged.

Information on new products and services received before 23rd May 2008 will be considered for inclusion in the next issue of Tidings.

Ray Goddard
Office Manager, Treasurer
and Trustee

Colostomates' Comments

For situations where no running water is available I would recommend Welland Ostagel. It comes in a 100ml bottle and is very easy to use.

Adrian March (CA Trustee)

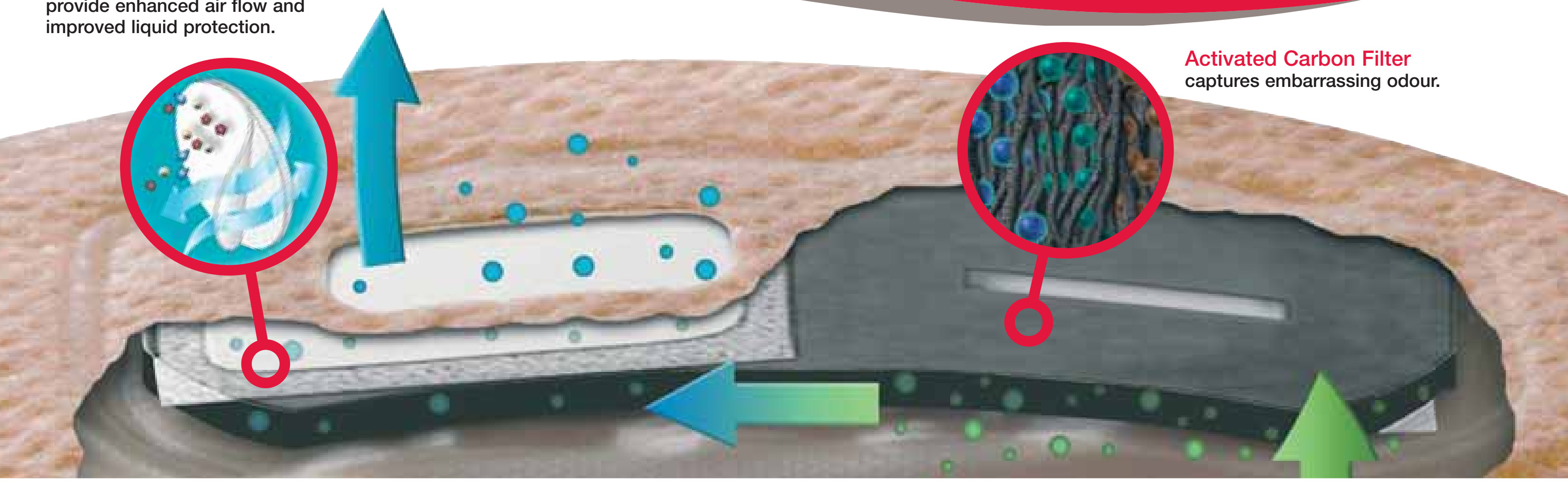
Colostomates' Feedback...

Have you tried a new pouch or other stoma care product recently?

If you found it to be superior to what you were previously using or it solved a stoma related problem, do write and tell us about it.

Tidings

Dedicated to Colostomates and their Carers



Coping with a Colostomy... and Arthritis

I am a new colostomate and have severe rheumatoid arthritis, which has had a big impact on how I cope with my colostomy. So I thought I would write and tell you about a few problems that have cropped up.

Firstly, I'll tell you a bit about my life. I am lucky as I have four lovely grown-up children who all live within a twenty-five mile radius. I also have four grandchildren under eleven and they give me such joy. In 1991, two years after our silver wedding, my husband left me for a "healthy younger model". My arthritis had started in 1983, but I had continued to work - running a petrol service station - despite being in severe pain.

Four years later I met someone else and we had ten years together, but sadly during that time I had severe problems with my arthritis. Arthritis is not usually thought of as life-threatening, but in January 2000 I underwent critical surgery in London as it had eaten away into my odontoid peg and my head was dropping onto my chest. They inserted two large bolts in my head at the top of C1/C2 vertebrae, dangerously close to the spinal chord. Failure to have this procedure would have resulted in paralysis or death - so there was no option. Six months later I had a replacement left shoulder, then in March 2004 a replacement left knee, followed by a left hip replacement in September of that year. Unfortunately my partner could not cope with my problems and we split up in January 2005.

So I started a new life in a lovely new home close to two of my children where I made lots of new friends and we had lots of fun trips out and holidays together.

Then in December 2006 I noticed blood in the back passage and after investigations was told I had a tumour. I went into hospital in May last year and had a laparoscopic anterior resection for a Dukes B carcinoma of the sigmoid colon. Five days later I was rushed back to theatre as I had developed peritonitis. I had to have a Hartmann's procedure to form an irreversible colostomy. I was told later that my colon was in a dreadful state due to all the drugs and steroid treatments I had been given in the past for my rheumatoid arthritis.

Then followed three weeks on ITU, which I do not remember much about. I did not regain consciousness for eight days and naturally my family were beside themselves with worry. My daughter wrote 'I do wish my Mum would wake up' in the diary of my progress, which I think just about sums everything up. I'm sure many of you readers will identify with the trauma our friends and family go through. After five and a half weeks I left hospital. Two weeks later I developed a parastomal hernia.

I've now been living with my stoma for almost nine months. My hands are very deformed with arthritis and I would really struggle to cut the hole in the flange to the right shape to fit around my stoma, so I send a template to my delivery company and they cut them for me. Changing the bag is also very difficult. Because of my bolted neck I can only bend and turn from the waist, so I can't actually look down to see what I'm doing. I usually take the bag off and clean around the stoma in front of a long mirror. To put on a clean one I lie flat on the bed which allows my large hernia to flatten then I raise my head and back and, with great difficulty, negotiate the opening of the bag around the stoma.

I've tried several types of bags and I do prefer the drainable ones which I can empty during the day. To keep changing the bag several times a day would be a nightmare for me. I did try a two piece where you leave the flange in place and stick a new bag on as needed, but I had problems with pancaking, so am now back on my one-piece drainable.

When I stand up the hernia tends to stick out so I put extra adhesive strips around the flange, as without them I would be nervous that the bag would come unstuck. I also wear two girdles. One is soft with very little support. The other is a much stronger and, although very difficult to pull on with my hands, once on it makes a big difference to my clothing.

My friends and I have just returned from a week's "high jinks" in Bournemouth and in a few weeks time we are off again: this time to the Isle of Wight. I have accepted the fact that my colostomy is irreversible and, like all of us, just count my blessings that I'm still alive and kicking.

Carole Hobbs

Need a loo...

In the last few months two readers have contacted us about toilets for the disabled...

RADAR keys are also available from the Colostomy Association

See back page for details of how to obtain one.

To ensure that we comply with the National Key Scheme rules we will require you to complete a declaration to confirm that you are eligible for a key prior to issue.

RADAR
the disability network

Dear Editor

One of the most useful pieces of advice I received after having my colostomy was to obtain a key for the disabled loo. You soon come to realise how difficult it is to change your bag in a conventional cubicle with no sink and no bin.

I have travelled all over the world since I had my operation and try not to let it hamper me. But one thing that is really bugging me is where do councils get their standards to be able to put up a sign saying Disabled Toilet? Having visited hundreds - some very memorable although not always for the right reason - I now put them into categories: The Good, The Bad, and The Unbelievable.

I think Jersey C.I. has to come top of my list: lots of them, and always clean. The USA has hundreds of signs but their only specification seems be a wide door; there is no sink and no bin. I thought I had found the ultimate when I used the disabled toilet on an airport main concourse and there was even a shower curtain – Wow! But where was the loo roll? On the far wall the other side of the curtain! At Preston Guild Hall there is no bin. Local golf course, which caters for about a hundred people, meals and functions, has no disabled loo at all.

When you find one it is always pleasing to see a shelf where you can put your changing bags. If not how many people have been caught out with automatic taps? No shelf so you pop your new bag in the sink and, before you know it, it's full of water.

And what about access?

Many places seem to keep the red sign showing occupied when it is empty, so they don't have to clean it. At M&S in Manchester you have to find a cleaner and plead to use the loo. At Preston Fishergate Centre you have to press an intercom button and they open the door for you - no key! I did get locked in last Christmas!

I have been challenged in so many places. In Manchester airport BA executive lounge I was told it was for wheelchairs only but did get in after I grovelled. I visited one in M&S where a man sat in the loo in his wheelchair. The door was wide open and he had a fifteen minute conversation on his mobile phone. When he did eventually come out he pointed to the sign!

What I would like to see is some sort standard and perhaps a blue plastic card saying disabled. I do have a card supplied by one of the companies, but it is bright orange and when I used it once I was asked was that B&Q or RAC? Perhaps you could help with this request.

Sincerely
Carol

Dear CA

I am writing to ask your readers for help. I have a colostomy and I am sure your readers will understand when I say that when going to a strange town the first thing you look for are the disabled toilets and how hard they are to find.

To solve this problem I have built a website http://needaloo.org, I am hoping to list every disabled toilet within the U.K. So far I have managed about 7000+. What I am asking your readers to do is visit the website and look for the area that they know and tell me if I have listed the disabled toilets correctly. If a reader knows of a toilet in the wrong place could they e-mail wrongplace@needaloo.org and if they find one I have missed e-mail foundaloo@needaloo.org.

Many Thanks
Chris Ryan

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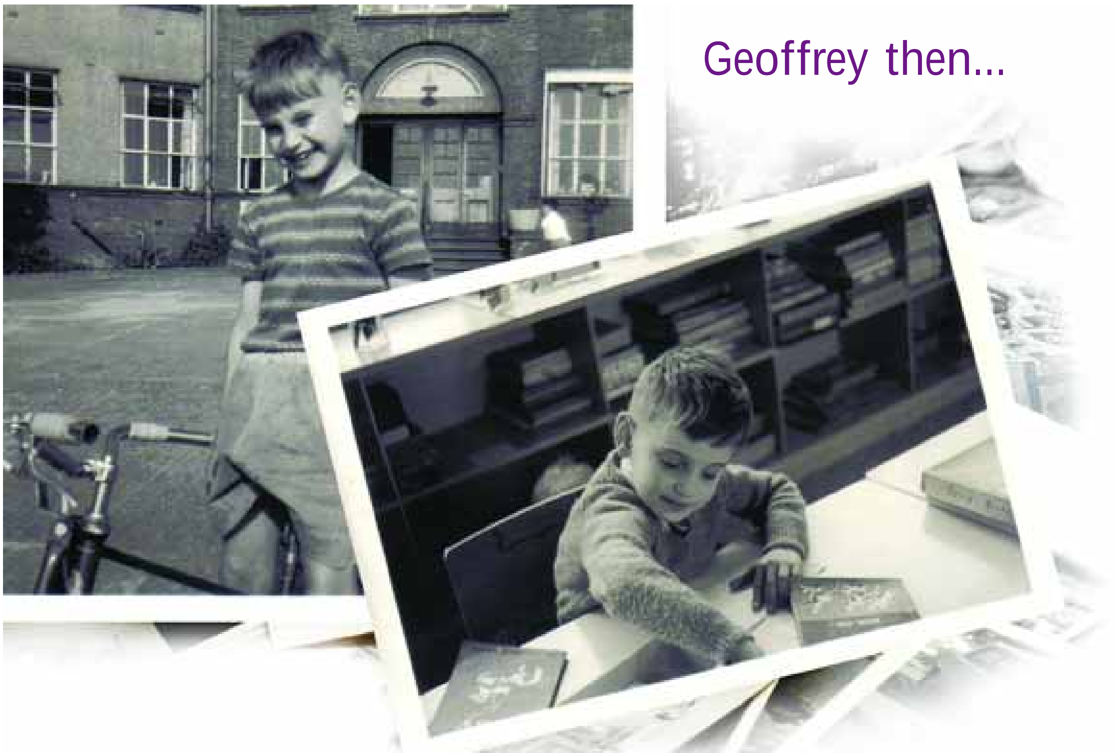


Geoffrey then...

Forty-three years as a colostomate...

Sid, my colostomy, became part of my life on 11th January 1965. I was just eight years old at the time and had suffered from a congenital condition discovered when I was just five days old. My colon didn't join with my rectum, and an exploratory operation did irreparable damage to my bowel muscles. From then on I was incontinent.

I was about six when I first encountered a colostomy. Big words didn't mean much then. I only knew it as a cherry. Some of the other kids had them in the Barnardo's home I was sent to for my early-years education. I didn't know why, but somehow I had the feeling even then that I would have a cherry. I guess I liked the idea of having a bag rather than being a nuisance and doing it in my pants.

The semblance of a normal life began on 11th January 1965. I awoke from the operation to the strains of the theme tune to the six o'clock news. The following weeks and months were spent in recovering, and learning all about my cherry. By this time he'd been named Sid after the boyfriend of the ward sister at the Bath Royal United Hospital.

When I was at the Barnardo's home the kids with colostomies had belts with bags. Imagine my disappointment when the surgeon insisted that I wear a corset! This was five or six inches wide. It was elasticated in places, and had hard strips of metal to help keep its shape. Just think of a Victorian corset with whale bones and you can't go far wrong. Instead of laces, the belt was fastened by a couple of sharp metal buckles. To stop the belt riding up there were two rubber-coated straps which went between my legs. And to protect my stoma from knocks there was a hard plastic shield shaped like a saucer about four inches in diameter to hold a patch of cellulose wadding.

I had four of these belts: two for day - and two for night-wear. One of each would be in the wash at any one time. And that was the thing with these belts: waste would gather in the cellulose wadding and often spill out from behind the shield. Holding that against my skin produced sores and irritation. It was also a smelly way of carrying around one's bodily waste. And being an active young lad sometimes the soiled wadding would work its way out and I'd go home wondering where I could have dropped it!

As I grew up the belts wore out and new ones had to be made. They came on prescription along with the wadding - about the only colostomy appliances that did at that time. The frequent sores I got, both around Sid and between my legs from the rubber straps, had to be treated by liberal doses of off-the-shelf creams. But there was other stuff I couldn't get on prescription - love and understanding, and a hefty dose of self-confidence.

There were times I felt a freak. I felt repulsive and unclean. I was never very far from unhappiness and depression. And so I sought solace in writing poetry and in the company of those people not in my family who saw me and not the infirmity.

A lot to do with my lack of confidence was the awful belt. There were no seals against odours, and strenuous physical activity sometimes meant soiled wadding escaping. There was also the looming prospect of intimacy with the opposite sex.

I just knew that at some time the belts would have to go. As I grew into adulthood it was becoming unacceptable to have to wear such a monstrosity. But I didn't know what was going on in the world of the ostomate. In fact, I didn't know that there was such a term as "ostomate." It wasn't until I moved with my parents to Bristol that I was even aware of someone called a "stoma care nurse."

It happened like this. I went to introduce myself as my GP's new colostomy patient. 'OK, drop your trousers, let's check you're not a fraud,' he said, perhaps thinking that I was a spotty youth having a lark. He was quite embarrassed when I showed that I did indeed have a colostomy. 'Well, I don't know about these things, you'd better go back to the hospital where you had the operation done.'

I was actually frantic. The belts I had were wearing out fast. The hospital seemed to be the only way, but who did I ask for? It was a 'I wonder if you can help me' phone call to the Bath Royal United Hospital. 'I had a colostomy operation over eleven years ago and I need some more belts and my GP doesn't know what a colostomy is, let alone know where to get appliances.' 'Please hold, I'll put you through.'

'Hello, Stoma Care Department.'
'Stoma care?'
STOMA CARE! A whole department specialising in STOMA CARE!
I was delighted. I was amazed. At last there was someone who knew about what I had and what I needed. I felt like Robinson Crusoe being rescued. It was "WELCOME TO THE WORLD OF STICKY-BACKED PLASTIC, CHARCOAL FILTERS AND PRODUCTS MOST DISCREET."

See how delighted I was? I was like a kid in a toy store at Christmas, and I wanted to try it all. The stoma care department at Bath were extremely helpful, but as I lived in Portishead I wasn't in their patch, so I went to Bristol Royal Infirmary where I was greeted with the same friendly, helpful manner.

I think at that time karaya gum was the thing. It was skin-neutral and was said to have good adhesion. Of course there's always one, and I was it. My skin got sore, the gum stuck too much, and the ring, it was attached to, got detached. The build-up of gas in the bags gave my lovely flat tummy an unsightly bulge, and when the seal broke it was like a gas attack. This was quite a frequent occurrence. My job had me sitting down a lot of the time thereby creasing my tum.

Filters? They worked OK if they didn't get soiled or damp. If they didn't work then I had a bag full of gas trying to find some exit and, when the adhesive really stuck, it was trying to get back the way it came!

I tried other pouches with non-slip adhesion properties. They would give a really firm seal even when my belly did crease. They were great ... until I tried to take them off. It seemed that the only way the bag would come off was if I were to take my skin off with it. Makes me wince even now.

As these trials were taking place I was working, meeting new people and falling in love... anonymously and unrequited. I couldn't see how I could get involved in a personal relationship lacking confidence in the appliances I was using. Whilst the pouches were less obtrusive than the belt I had worn, there was still the problem of broken seals and smells. And what's more, I wasn't used to carrying a bag heavy with waste, it had all been up close against me before, but now I felt the thing dangling. Something had to be done.

Again the stoma care staff came to the rescue.
'Ever thought of irrigation?' they said.
'Irrigation? What's that?'
'Wash your colon out two or three times a week and just wear a stoma cap.'
'Stoma cap?'
'Small, light patch over your stoma. Looks nothing more than a plaster. Great for your figure!'

It was. It was great for everything. It was the most liberating thing to have happened to me since having the operation done. Not only did it rid me of bags full of gas and waste, it made me feel healthier, and better in myself. The tiny stoma cap felt like nothing, and looked like nothing. And with that it made me feel that I didn't have a colostomy at all. It was only when I was in the bathroom doing the irrigation that I felt any different.

This simple procedure done regularly gave me the confidence I needed to get on with my life. I had wanted to do what everyone else was doing, and now I could. I didn't have the baggage of a cumbersome belt or a heavy pouch. The only balloon I had was the feeling of light-headed confidence.

It took some time for that feeling to grow. I had gone through years of struggle and was somewhat conditioned to feelings of unhappiness. But eventually happiness was fulfilled in meeting my wife, Lynn, and finding in her deep love and understanding, and acceptance of Sid. We've been married now for over twenty years with Sid still there, a minor inconvenience at times, and only getting between us in the nicest possible way.
I'm grateful that over the years such great strides have been made in the development of the many varied ostomy products, allowing each one of us individuals to choose those which suit us. Forty-three years ago there was no such choice, and at times my life was a misery because of it. I hope that my fellow ostomates will continue to have such choice so that we may enjoy the same quality of life that others without stomas do.

Geoffrey Newman
Bristol

Geoffrey now...

Rectal discharge...

Penny Fitzgerald RGN, BSc (Hons),
Stoma Care ENB 216
Colorectal Nurse Specialist
Countess of Chester Hospital.

Jill Dean RGN, MMedSci, BSc (Hons),
Stoma Care ENB 216
Professional Services Manager
Coloplast Ltd.

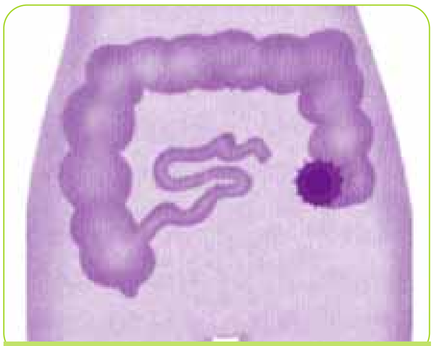
The aim of this article is to answer some of the questions about rectal discharge, explain why it might occur, what causes it and to explore some of the management and coping mechanisms that may be beneficial. The article and the suggested advice are supported by a recently conducted survey of 150 people who shared their experience of living with rectal discharge and pain problems following surgery with stoma formation.

Many people with a stoma experience discharge from the back passage despite the fact that they have a colostomy. Rectal discharge and whether it causes problems varies from one person to the next and, as it's quite a private issue, many people don't talk about it making the size of the problem relatively unknown. Rectal discharge also depends on the type of surgical procedure performed and whether the rectum was removed or retained. The most common type of rectal discharge is caused by mucus.

What is mucus?

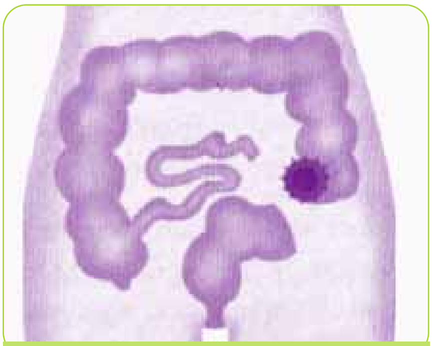
The lining of the whole of the bowel continuously produces a substance called mucus which acts as a lubricant to assist the passage of faeces. In a person who has a normally functioning bowel mucus is not usually noticeable as it mixes with the stool and passes directly into the toilet.

Will everyone with a colostomy have mucous discharge?



Abdomino Perineal Excision of Rectum or APER

Not everyone with a stoma will have mucous discharge from the rectum. For example one of the most common surgical procedures resulting in formation of a permanent colostomy is called Abdomino Perineal Excision of Rectum, or APER for short, and involves removal of the rectum and anus. The end result is a scar in the area where the anus used to be and once this has healed there is no external bowel opening.



Hartmann's Procedure

Other surgical procedures, such as a Hartmann's Procedure or the formation of a loop stoma, where the rectum is left in place, may produce mucous discharge. This happens because the bottom part of the bowel becomes redundant as faeces no longer pass through it but the lining of the bowel wall still continues to secrete mucus. It is the mucus that causes problems as it no longer has a useful purpose.

The mucus can build up and either leak out of the rectum or dry up into a ball and cause pain. The frequency and amount of mucous discharge is very individual ranging from every few weeks or even months to a constant problem several times a day. The length of bowel that is left behind varies according to the surgery and the procedure performed.

Loop Colostomy

However, the longer the length of redundant bowel the more likely it is that you will have problems as there is capacity for more excess mucus to be produced.

Loop Ileostomy

Mucus should always be clear or putty coloured unless you have a loop stoma which can sometimes allow a small amount of faeces to pass into the bowel leading to the anus in which case it would make the discharge brown.

Is it normal to have a mucous discharge from the rectum?

Surgeons and health professionals will say, 'It is normal and don't worry'. This can be reassuring but frustrating as it does not help the physical problems that you have to live with. Mucus varies in consistency from clear "egg white" to opaque thick "sticky glue" both of which are considered "normal".

How do people cope?

Most people appear over time to develop their own coping strategies. It is very important to understand you are not suffering alone and other people are experiencing the same problems. Discuss your fears and anxieties with your partner or someone you can trust. It is a normal function of the body to produce mucus so it will not go away. Some people, however, report a significant reduction over time.

Many of the suggestions came from the survey results and are therefore "tried and tested" by people living with a colostomy and experiencing problems with rectal discharge.

1. The most effective way of management is to sit on the toilet daily and gently bear down as if you were to have your bowels open. You should be able to evacuate mucus naturally. This reduces the risk of build up, which may lead to pain, and also reduces the amount of mucus that leaks out in an uncontrolled way.

2. If the mucus won't come away naturally (some people say they don't have enough sensation in their rectum to push) a glycerine suppository inserted into the anus may help. You could discuss this with your GP who would be able to prescribe them if he felt it would be appropriate. The frequency of using the suppositories to control the mucus varies between individuals. It may be necessary to use them twice a week; it may be once a month. Persevering and experimenting with the frequency will achieve the best result for you.

3. Although there does not appear to be any reported scientific evidence for this suggestion, several people reported a link between certain foods and an increase in mucus production. It is worth just keeping a record of foods you have eaten for a while to see if you can find any connection.

4. When the mucus leaks out it can make the skin around the anus sore (like nappy rash). There were many suggestions of specific creams to help this eg. Sudocrem and Cavilon. Basically, if you try the different barrier creams available from the chemist you will find one that may suite you best. You can always ask your local pharmacist for advice. For ladies the application of barrier cream can also reduce the stinging caused by urine splashing the excoriated skin. The cream can also be applied to a small pad or gauze dressing which can be held in the cleft of the buttocks.

5. Regular showering and dab drying (rather than rubbing) will remove the moisture, odour and keep the skin clean. It will help reduce the skin irritation and itchiness caused by a permanently damp anal area. Using wet wipes can also help to clean the area, especially if out and about or at work. Reapply creams or barriers after washing or cleaning.

6. In the survey pads were popular to protect clothes. The biggest complaint was that they were bulky. You can make your own pad from kitchen roll or gauze swabs, or use a ladies' panty liner. Good fitting traditional underpants for a man, or stretchy support knickers for ladies, will hold it in place.

What if there is blood or pus in the discharge?

If the rectal discharge is blood or pus, or the mucus is streaked with blood this should be reported to your GP or consultant as it may be an indication of inflammation or infection. There is some evidence to show this may happen because in some cases the remaining redundant bowel becomes inflamed, a condition known as diversion colitis. Those who had their surgery for ulcerative colitis or Crohn's disease may be at risk of inflammation due to disease affecting the redundant bowel and some people will require treatment with enemas, foams or suppositories into the rectum.

Discharge and/or bleeding may be caused by an abscess, polyps, piles or fissures. People who had their surgery for bowel cancer are at slightly increased risk of another cancer developing in the remaining bowel. Examinations to look at the redundant bowel may be undertaken if symptoms occur, or are sometimes done routinely at the same time as other bowel examinations.

This article has described some of the problems colostomists may face if they have rectal discharge. We hope it has helped you to understand why this occurs and that if you experience this type of discharge the shared experiences of ostomates who replied to our survey will be useful.

Don't forget that any rectal bleeding at any time, discharge or other changes - in fact anything that is not normal for you - should be reported promptly to your GP or consultant.

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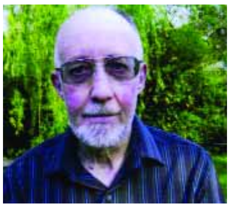
Coping with Rectal discharge... Two colostomates share their experiences



In August 1999 I had my colostomy due to diverticulitis. After intermittent constipation over a period of only a few weeks I was admitted as an emergency to the Good Hope Hospital in Sutton Coldfield. I recall being told in the pre-operation chat that the worst scenario would mean waking up from the anaesthetic with a “bag”. I had only a vague idea what a “bag” was. After the operation, which was a Hartmann’s procedure to form a stoma on my left side about three to four inches below my waist, it was a quick learning curve. However, with the support of my family I got used to the idea.

I remember being told, before leaving hospital, that in six to eight months time I would be able to go horse riding, skiing, swimming and hang-gliding. I thought this will be great fun and remarkable as I couldn’t do any of these activities before! While I am in a light-hearted mood, before the slightly embarrassing part of my article, I recall another amusing incident a few days after returning home. My wife, Pam, and I were lying in bed when suddenly there was a rustling sound coming from under the duvet. Pam said, ‘Are you hiding crisps in your pyjamas, Mike. If so where’s mine?’ Our laughter broke the ice about a delicate subject, creating a personal joke of the situation and bringing us even closer together.

It wasn’t until I came home that I had my first experience of a discharge from my rectum - despite having a stoma. I was a bit alarmed and as it was dark in colour my first thought - silly in hindsight - was that the internal connections hadn’t been done correctly! A phone call to my doctor, who contacted the surgeon, assured me that this was a normal postoperative occurrence due to blood residue etc left inside which would disappear in a few days – which, of course, it did.

I was advised by the nurses that when recovering from surgery it is very important to do the pelvic floor exercises which strengthen the appropriate muscles to control any discharge. This discharge is a natural body function as mucus is produced as an anal lubricant.

Personally I find how often I need to pass this discharge varies with both how much I eat - extra large meals can increase it - and my general health - stomach upset, stress and excitement can have the same effect. Very occasionally, and I must stress very occasionally, if the discharge increases for extra peace of mind I have used Pam’s panty liners inside my underwear.

I hope this short article may be of some help to fellow colostomates and I am willing to talk to others who have a similar problem. The Colostomy Association have my phone number if required.

Mike Tomkins
C.A. Volunteer, Sutton Coldfield

In 2004 after bowel cancer I had a loop colostomy. The whole time I had the stoma I was constantly visiting the toilet because of a discharge of a yellow liquid from my rectum. Tena Lady pantees and pads were my “life-saver” until my stoma was reversed six months later.

In 2007 I had a blockage which led to perforation of my intestine. I had emergency surgery to remove part of my small bowel and an end colostomy was formed, leaving my rectum in place. The first two months were wonderful – no rushing to the toilet. Then rectal discharge of mucus started again. At first it was every two or three days. Then it became more frequent.

I now have a mucous discharge two or three times a day - red or pinkish coloured. I have been told that it is this colour due to internal and external piles. If there are signs of blood in the discharge it is always important to get this checked out by a doctor.

I cope with this by using a pad, then placing several pieces of toilet paper between my buttocks in case of emergency. Once the mucus has come away I don’t usually have any leakage onto my underwear.

My specialist suggested using a self-administered enema once a week to get rid of any residue. I have not done this yet. I just live in hope things will improve. I would be interested to read of any other ostomates who have this problem.

Ann


Appeel
No sting
Medical
Adhesive
Remover
Order Code: 3500
Appeel
No sting
Medical
Adhesive Remover
Order Code: 3505

Readers' Replies...about hernias

In the last issue of Tidings we included articles about parastomal hernias written by health professionals and two readers' accounts of how they cope with a hernia. We asked you to write in and let us know about your experience of parastomal hernias and operations to repair them.

Dear Editor

I was diagnosed with colon cancer in 1976 and had an operation to form a colostomy at St Mark's Hospital in London - No problem, no chemotherapy and after two years they said they didn't want to see me again. About four years later, when I was about sixty-five years old, I got bouts of severe pain and my doctor referred me back to St Mark's.

I had a hernia, but they didn't really want to operate. They said they doubted my muscles would be strong enough to hold and that they may well have to move the stoma to the other side. However, the pain was so severe that in the end they took me down to theatre.

They operated successfully and I have a second scar across my tummy. There have been no problems since.

Yours
H.M.R.

Dear Editor

I have two stomas: a urostomy since 1997 and a colostomy since 1998. Without going into all the history I thought I had come out of things very well especially when I read in the magazine about the problems other ostomates were having. I am eighty-three and a few years ago I felt the time had come for some additional support.

I studied the market and tried a corset and the Eakin belt which had been recommended by a stoma nurse. However, I was not too confident about the waste being able to pass into the bag. I had good experience of clothing manufacture and decided to experiment by inserting a cotton patch with holes into the belt which would allow me to pull my pouches to the outside of the belt removing the possibility of the belt impeding the flow of waste. This proved very successful.

I would definitely recommend the use of an acceptable support at an early stage - I wish I had worn one sooner. You need to discuss it with your stoma nurse to get her approval then she will measure your abdomen and issue a prescription for a belt of the correct size. I would suggest you wear the belt for short periods to get familiar with it.

As I already have two hernias, to put my belt on I need to spread it out on the bed and lie on top of it. I relax my abdominal muscles before pulling the belt across my body and fastening it at a comfortable position, not too tight. When I stand up I move the belt round to the best position while holding my stomach in.

I have been wearing a support belt for approximately three years. I wear it all day long, only taking it off before going to bed at night. It is a great asset enabling me to do things which had put a great strain on my two parastomal hernias especially when lifting and walking.

Yours sincerely
H.B. (Mr)

Dear Editor

In 1974 I had a colostomy and an AP resection for cancer. After six months I went back to work and was reasonably well for ten years.

Then trouble started. At first my parastomal hernia was small but it grew much larger and eventually my surgeon had to operate because of the pain I was enduring. That was in 1992.

In 1993 my hernia returned and I had an operation to repair it and refashion my stoma. Then the following year I developed an obstruction and needed another operation. In 1996 I had another hernia repair and my stoma refashioned, but this time the surgeon put mesh inside. In 1999 after having terrible pain a fistula appeared near the stoma and burst and I was admitted as an emergency. After ten days of antibiotics I had more major surgery when the stoma was re-sited to the other side.

To crown the lot I now have a parastomal hernia on the right side and also on the left side where the stoma used to be. Surgeons will not operate on me unless I strangulate or obstruct. So, up to date, I have had the stoma moved five times.

Yours faithfully
H.M. (Mrs)

Dear Editor

In 2004 after many years of suffering with severe ulcerative colitis I was given an ileostomy. This operation changed my life completely - for the better.

Unfortunately after about four months I developed a parastomal hernia which caused me problems keeping the bag attached. After trying to get by using a Sash support belt and CUI support garments I saw my consultant. He suggested I have my hernia repaired and my stoma moved from the right side of my body to the left. Understandably I was a little wary of undergoing further surgery, but I decided to go for it. So almost twelve months after my first operation I had surgery again.

The operation was a great success and I have never looked back. I spent two weeks in hospital and was then visited at home by the district nurse for about a week. Since then I have retired and my wife and I have travelled to Canada and America - a trip I would never have dreamt of taking before my ileostomy.

Yours sincerely
R.A.G. (Mr)

Colostomates' Feedback...

Do you have a parastomal hernia so close to your stoma that support garments currently available are ineffective?

Adrian March, CA trustee, is collating information on the size and position of these problem hernias to determine if it might be possible to provide a solution. If you would be interested in helping Adrian with this research please e-mail: adrian.march@orange.fr

Tidings

Dedicated to Colostomates and their Carers

Update...

on Department of Health and Scottish Government Consultations

Representatives from patient associations, including the Colostomy Association, attended a meeting in London on 26th February. The Department of Health provided an update on the ongoing consultations impacting on stoma supplies.

Key points

from the meeting were as follows:

- Consultations closed 28th December 2007.
- Over a six week period, to 14th March, discussions took place with representatives from the stoma care industry.
- A classification panel met between mid February and the end of March to review all of the feedback which was provided on the comparability of products. This panel consisted of representatives from industry, nursing organisations and patient groups including CA.
- A summary of the responses to the consultation will be published on the Department of Health (DoH) website on 28th March. This will also include general themes from the large number of letters that the DoH received.
- A number of options for the way forward will be presented to the Minister of Health by the end of March.
- Following the Minister's review of these options a further consultation is likely to be published in May with a twelve week response period.

Although there is still no firm outcome to these consultations, the Department of Health do appear to have listened to the concerns raised by all parties and, hopefully, the final Consultation will be acceptable to all sides. Please visit our website www.colostomyassociation.org.uk for updates on this process.

The position in Scotland is still giving cause for concern and we would be pleased to hear from any of our Scottish members who are encountering problems with the supply of equipment or restricted choice. Discussions are still at an early stage, but there is likely to be a consultation document in Scotland which will outline their proposals for the future.

Ray Goddard
Office Manager, Treasurer
and Trustee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Free the planet."
(FREESTYLE® FLUSHABLE USER)
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Dear Nurse...

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

Q: I normally manage my colostomy by irrigation, but when I picked up a tummy bug earlier this year, I wasn't sure what to do. Should I continue to irrigate? I had diarrhoea for four days. I irrigated twice to try and clear it all, but anything I ate or drank just kept on going straight through. At this point I wasn't sure whether to take Imodium to stop it or just keep on drinking water.

I would be grateful for some advice in case this should happen again.

A: I would suggest that if you have a similar situation again to discontinue irrigation until the problem settles. Once you are back to having a normal output you can then start to irrigate. It may take time for the irrigation to settle into a routine again. The use of Imodium for diarrhoea is fine but you need to be careful that you don't take too much and cause constipation.

Q: I am a carer for my eighty-six year old grandmother who has had a colostomy bag since January 2007. There was no diagnosis of cancer. The consultant mentioned a "fistula".

Recently she has been experiencing rectal pain and discomfort, and has the sensation that she needs to pass a motion urgently. I was wondering if you could provide any advice as to whether or not this is normal or should we perhaps seek further advice?

A: You do not say whether your grandmother had her back passage left in place, although I would think this was the case. If she still has her back passage then it is normal to pass mucus or to get the sensation that she needs to go to the toilet via her rectum. It would be advisable to visit the GP to get her rectum examined. He may be able to get a district nurse to visit your grandmother and give her a glycerine suppository which would clear the rectum of any debris if she is finding it troublesome or cannot pass the debris herself.

Q: I was diagnosed with Crohn's disease at the age of fourteen. That was in 1976 and since then I have had four bowel resections. The third resection resulted in a potentially temporary colostomy, but a further Crohn's flare-up resulted in the stoma being re-sited in a less manageable position. Since then my Crohn's has never allowed the stoma to be considered for reversal.

In the last year on three occasions "out of the blue" large quantities of blood have filled my stoma bag. The first time this happened I was tested for an ulcer or for any bleeding from the Crohn's. It happened once more in August 2007, but this time an arterial bleed from the actual stoma was discovered. The surgeon stitched it on the ward and it calmed down. Then again I bled profusely, was seen by surgeons who found a separate bleed from a vein at the opening of the stoma and once again it was stitched.

As you can imagine I am somewhat uneasy about the viability and efficiency of the stoma now, worried when it will happen again and not sure what is the best long term outcome. Do you think that I should be considering a further re-siting? Have you come across this localized excessive bleeding which cannot be resolved without stitching before?

There seems to be no direct link with anything I do and the bleeds starting, and as such I cannot do anything to stop it from happening. I really need advice and also to find out if others have experienced similar bleeding.

A: Although this is not a common occurrence, I have had patients with this problem before. If the bleeding is excessive then it is usual for the medical staff to suture the blood vessel to stem the bleeding. Obviously I am unable to comment on the cause of your particular problem or the need for re-siting of the stoma again but I would suggest you visit you consultant surgeon again to discuss the problem in detail.

Q: I am an almost fifty-one year old female and have a urostomy. I have had terrible diarrhoea for many years and I currently have an artificial sphincter. However, this cannot cope with diarrhoea. I find this very depressing and am beginning to seriously consider going for a colostomy, despite the fact that I would have a second bag.

I would be very grateful for some information. I would really like to know what happens with diarrhoea when you have a stoma. Would this stop it or at least would a bag contain it? I have many adhesions from various surgeries and radiotherapy twenty-two years ago - when it was not as refined as nowadays and did much more damage. .

A: If you had a colostomy fashioned you may still have diarrhoea but with the correct product this should be manageable. If the motion remained loose you would probably be best using a drainable bag which can be changed for a new pouch every two to three days but with the ability to empty the pouch between the changes. If this is a path you feel would be helpful to you in your situation I would advise a discussion with both a colorectal surgeon

Dear Nurse...

and your local stoma care nurse. It may be possible for you to talk to other patients who have had surgery resulting in two stoma pouches and can provide support and information from the patient's viewpoint.

Q: My husband had his first ileostomy five years ago, then developed a parastomal hernia, which meant that last October they moved his ileostomy to the other side. He has no big bowel and only part of his small bowel as a result.

He was told at the time not to eat anything that was stringy or had shells of any kind and tomatoes and grapes should be skinned. He has taken care to observe these details and is in super shape now.

I was very surprised to read about this seventy year old colostomate eating coleslaw and sweetcorn in issue 7 of Tidings and would like your comments on this subject.

A: The dietary advice given to colostomates is different from that given to ileostomates. Basically, those patients with a colostomy are able to eat or drink anything. However, patients with an ileostomy are advised to avoid anything with fibrous skins and to drink plenty of fluids to avoid possible blockages or dehydration.

Following a question about sore skin on the Dear Nurse page in the winter issue of Tidings three readers sent in their comments.

I used to suffer from sore skin especially around the edge of the stoma bag where the adhesive used to take the skin off sometimes leaving my skin bleeding. I used barrier creams and everything else which was suggested but the problem was still there. Then I received a sample in the post. It was Silesse sting free barrier wipes (ref TR 103). Since using this product not only has my skin around the stoma been great - no sore patches – I've also had no leaks. I have to use the sting-free medical adhesive remover (REF TR 101) to remove the bag as it's stuck on so well. My life has changed because of one product. Please could you pass this information on to this lady as I think this product might help.

I wear a two-piece colostomy appliance and change the flange twice a week. After cleaning all around the stoma I use barrier wipes on my skin. Barrier wipes are sterile and soaked in substance that dries on the skin. I use two wipes, letting each one dry separately so that I have two layers of barrier film. These dry completely in two to three minutes, the flange sticks perfectly and I have no problems with sore skin.

Regarding soreness from the adhesive flange, Salts produce hypo-allergenic protective wafers (Product Code PW1010), which can be interposed between the bag flange and the skin, and should cure any allergy problems.

Julie replies

There are many different products on the market for use with sore skin, leaking pouches and other stoma related problems. However, as we are all individuals in our own right what is suitable for use by one person is not always the correct treatment for another ostomate. I am glad to hear that these products worked so well for you and the use of skin protective barrier wipes and protective wafers, of all sorts, are still an option following review by the stoma care team.

Dear Nurse...

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.

Reader's Story...

Former model Sharon Moore tells us about her life...

Sharon with Bavan, an eighteen month old snow leopard.

I was formerly a model and had been since the age of eleven - mainly fashion and television work as a teen, moving into topless modelling in my twenties. I also did a lot of exhibitions, shows and camera clubs nationwide.

Ulcerative colitis resulted in my bowel becoming perforated and having to have an ileostomy when I was thirty.

This ended the modelling as I could no longer drape myself over luxury yachts and cars. It was also pretty difficult to disguise my ileostomy as I've always been very trendy and adored skimpy clothes showing off my golden tan and trim figure in midriff-baring little numbers.

This led to a complete turn-around in my career. I did a degree in public relations/media and journalism and went into freelance journalism doing mainly investigative features including a lot of health documentaries for TV.

Nobody knows I have an ileostomy till I tell them. However, having an ileostomy that can't be reversed has had some very profound effects on my life. There have been some awkward moments as well when bags have leaked but I try to cope with it as well as possible and have adapted my life to suit.

I still wear my sexy, figure hugging outfits but now with a wide belt or a handbag on a long strap worn sideways to disguise the slight bulge. I have a parastomal hernia which is inoperable and so I wear support knickers instead of skimpy ones, but thongs just the same. ASDA George range includes control briefs in a thong style that cover the pouch and still make me feel attractive.

Occasionally I get hospitalized as I get blockages. I have learnt to stay away from certain foods that cause me problems such as potato wedges with skins, lentils and mushrooms to name a few. I can't eat big meals either or I am sick but I still manage to be greedy at times.

On the man front I haven't one currently. If I am in a relationship I eventually tell them what has happened to me, and it is not usually a problem. I wear a lot of sexy underwear like basques, which cover it all up.

Unfortunately, I had a double whammy as a few years after my ileostomy I had cancer in my right breast so have had a mastectomy as well!

My hobby is big cats. Unusual, I know, but I have been around them since childhood and am involved with a leopard charity. They are mainly snow leopards, pumas, jaguars, lynx and caracal. They are no different to your domestic cat and love a good old fuss. One day I hope to have my own leopard sanctuary and my own cats.

I am also a Hepatitis C rights campaigner and have my own e-petition on the 10 Downing Street website. I was given Hep/C in an NHS blood transfusion in 1987 and, even though I was very ill at the time, I was denied compensation being a "natural clearer". My fight for my rights has taken a decade and I am confident I will win in the end and keenly follow the independent inquiry into contaminated blood.

Having an ileostomy can be a real bind at times, but there are worse things. For me having breast cancer and losing a breast was far more traumatic. Aged forty-eight now, me and my stoma have been through a lot...and survived!

So chin up, all you other ostomates.

Sharon Moore

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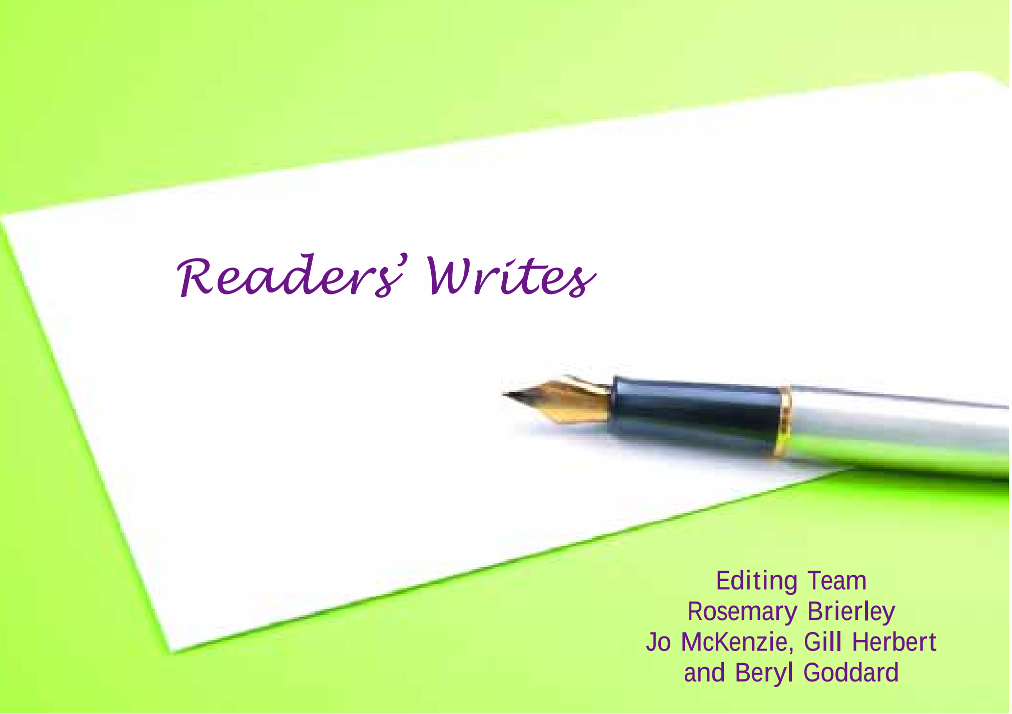

Readers' Writes

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

Dear Colostomy Association and Tidings

It is thanks to a special lady, Barbara Orlans, from Liverpool that I am where I am today. Her positive advice and direct approach has had me well on the track right from pre-op and through questions and solutions to the well adjusted ostomate that I am now - nine months on.

Of course we are all "ice skaters", no matter how well we cope. Life can get in the way and we are on a bit of an adventure. Tidings and its advice, samples and stories is informative and inspiring. This last year I have experimented with different products. The manufacturers have been very helpful, but I have still not found my "dream" appliance.

Special thanks for being there for all of us
Regards
P.O. (Mrs)

Barbara is one of over seventy CA volunteers throughout the UK. All have a colostomy themselves and are happy to visit others before or after stoma surgery. Our volunteers can also listen to concerns and pass on information and practical advice by telephone or e-mail. Ed.

Dear Editor

I had my colostomy due to rectal cancer in 1993. Four months after the operation my wife and I had a holiday in Madeira. Since then we have regularly taken holidays. During the last year, in which we celebrated our golden wedding, we have visited the Canaries (twice), Austria, Belgium and Norway, where we went snowmobiling and dog-sledging.

I use a two part system and find that it is useful to prepare two weeks supply of spare bags before the holiday. I include a spare bag, a wipe, a disposable glove and a disposal bag all folded together. This makes changing a quick, uncomplicated procedure. After emptying the bag and placing everything in the disposal bag I then place it in a nappy sac. All this ensures that everything is disposed of without any residual odour.

I have also found that my insurance company were very happy to offer full cover once I had received the five year all clear with the obvious proviso that I should advise them of any material fact that might affect my condition.

I swim twice a week, usually twenty lengths, and enjoy a glass of wine most days.

Your sincerely
B.C. (Mr)

Dear Editor

I had my operation for bowel cancer on 25th May 2007 and I manage, wearing Patsy (my pouch), very well. I go to gentle Keep Fit and also line dancing once a week. I also go on plenty of trips out with my lady friends so my outlook on life is much the same as before the operation. The only worry is – my surgeon has fixed a date to see me to talk about a reversal. He says I'll be fine, but after reading some of your letters it worries me as to how it will affect me. I am eighty in May this year and at the end of the day I'll have to decide one way or the other.

I enjoy Tidings very much as it lets me know I'm far from being on my own with having to wear "Patsy".

Thank you again for being there if I need any advice.
R H. (Mrs)

In our last two issues of Tidings we included a checklist of the questions to ask your surgeon about the reversal operation he is proposing. His answers should help you to make up your mind. If you can't find these questions or would like to talk it over with someone, call our helpline 0800 328 4257. Ed.

Dear Editor

I had my operation for bowel cancer ten years ago at the age of seventy-one after a prolonged spell of severe bleeding from the back passage. Although I had no pain I had been troubled with constipation for a long time. There were complications with the operation and it had to be repeated and as if that wasn't enough, my bladder went on strike and I had to use a catheter which I found very difficult.

My hospital stay covered Easter, Mother's Day and my birthday. The cards and presents piled up, but all I wanted to do was to have a "wee". It was a matter of great interest to the other patients in the ward as well. All looking up expectantly each time I returned from the loo where the nurse turned all the taps on to full flow as encouragement while I sat hopefully. 'Any luck?' they'd chorus but my gloomy face was enough answer. The doctors would pass the door pausing to mouth silently 'Any luck?' and I'd smile bravely with a shake of the head.

When the doctors decided I could go home I was both overjoyed and terrified...what if I couldn't manage the catheter? It did take some time and there was plenty of anxiety till, miraculously, one day it happened. The phone bill soared as I announced the news – 'I've had a wee!' Rejoicing all round.

Meanwhile I was learning to cope with my stoma, with the help of my wonderful stoma nurse. Everyone has been so good to me that in spite of everything I feel very lucky. It took a long time to regain strength and for a while I had to use a wheelchair. (I am not going to depress you with the story of my sciatica so breathe a sigh of relief!) More people to be grateful to – the Social Services. So many kind and caring people who rally round in times of need.

Eventually I was ready to live life again without feeling like an invalid. There's no doubt that other colostomates' stories can be an inspiration. When feeling very weak after my operation I heard of an acquaintance who had lived with a colostomy for six years yet travelled abroad each year on holiday – and he was no spring chicken either. I thought if he can do it so can I.

My daughter and her husband took me on holiday to Lake Garda - my first flight at the age of seventy-two. The following three birthdays found me on flights to Malta, Rome and Paris, dashing around these cities on the heels of a lively granddaughter determined to cover all the sights in the space of a weekend.

Sorry to go on for so long, but before concluding I must mention that I've had a parastomal hernia for three years. I have wondered if it was caused through carrying heavy shopping. But I get support girdles on prescription and find them very helpful.

Yours sincerely
J.G. (Mrs)

Dear Friend

I am in my ninety-third year and have had a colostomy for the past three years. Unfortunately I have rectal cancer and after three lots of surgery and radiotherapy the tumor is still in position making it painful to sit down.

However, I have partially solved the problem by using children's swim rings which when inflated leave a hole in the centre which reduces the pressure on the rectum. These are quite inexpensive to purchase and when punctured can be easily replaced. I am sure this information may be of use to other friends who may have the same problem.

Yours sincerely
A.B.

Dear Editor

The articles and letters on various issues in Tidings have been informative and helpful. In particular the recent comments on reversal were relevant to our consideration about a reversal operation last year. Advice in the latest edition about avoiding hernias is also very pertinent to my position at the moment.

As background, let me describe my situation. Following surgery in 2006 to remove a tumour in my rectum, the join leaked and after a further operation, I found myself with a stoma. Because it was emergency surgery the stoma ended up in the wrong place – right in the crease on the waistband – and it became stenosed. Although I was eventually able to manage the bag quite well, the area around the stoma was often very sore and this was quite debilitating.

Early last year we took a coach holiday to Austria and Switzerland, partly to see how I got on with the bag. It went well and that encouraged us to take a successful five week motor home holiday in north and west Australia in the autumn. I found it helpful, though not essential, to use disabled toilets when changing the bag. When I asked about their availability at one site I was able to help a lady who was being urged to consider a colostomy, but without being given any information about what was involved. I do think it is good if you can talk openly about having a bag.

After considerable thought and discussion with the consultant, based on an assessment I did of the pros and cons of various options - no surgery, a full reversal or just re-forming the stoma - we decided to go for the reversal. This was on the basis that if, on opening me up, the surgeon felt the reversal was not practical, then she would simply deal with the stoma. I had the operation on 1st November and the reversal itself went well. Unfortunately I needed further surgery as the join in the small bowel leaked and a fistula formed. I then developed clostridium difficile, which was uncomfortable and prolonged the hospital stay to five weeks.

Now eleven weeks after the reversal things are going well and the bag seems like a distant memory. However, as I was warned, reversal does not mean things return to "normal". The new "normal" is more frequent bowel movements and at the moment I have to work at trying to establish a more regular pattern. Having to get up during the night, sometimes more than once, is a nuisance but it is happening less as I learn to ignore feelings. And at least I usually have sufficient control to avoid using the toilet during the day. So I am one of the lucky ones. I think reversal was right in my case, although I did not necessarily think so in the weeks immediately after the operation.

Yours faithfully
K.L. (Mr)

Dear Editor

It is now nearly a year since the Symphony stoma bag was discontinued on 1st February 2007 when Mentor Medical was taken over by Coloplast and the company took a marketing decision to cease production. Has anyone noticed?

Having used Symphony bags for sixteen years, I was forced to move to the only alternative flushable bag called the Welland Freestyle Flushable. When I questioned the situation, I was told I was one of a minority of people who chose to use Symphony bags, and therefore it was not commercially viable.

Symphony stoma bags were uniquely fully flushable and considerable technology had been applied to development. Coloplast chose to cease production, without a flushable alternative within their range. The only alternative product produced by Welland is only partly flushable. It is necessary to dispose of the outer part of the bag in the dustbin. Another aspect is that despite a recently modified inner liner, the Welland bag is quite noisy
I am surprised that so few people choose a flushable bag over a conventional one. Disposal is an inconvenience to many people, so why is it that so few people value the flushable bag? Do they know about them?

Readers' Writes

Some people choose to use flushable appliances, some are happy to dispose of their appliances in the rubbish. In a world that is becoming more sensitive to how we dispose of our waste, I would have thought that a fully flushable bag is preferable to the Welland one which leaves a non-flushable outer bag for disposal elsewhere.

What do you think?

Yours sincerely,
P. B. (Mr)

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.

Bag or Pouch?

In the last issue of we asked if, when we refer to a stoma appliance in Tidings, it is better talk of pouches or bags.

Here are your replies.

I have a colostomy but am not a "bag lady", so I have never called it a bag. We have always referred to my pouch – as it is supplied by Pelican!
P.S. (Mrs)

I always refer to my pouch as 217: B being the second letter of the alphabet, A the first letter and G the seventh. I think pouch is a nicer word, though, when writing about them in "Tidings", don't you?
S.C. (Mrs)

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Marketplace

If you have anything to sell, an event to advertise or a message to communicate, you can place a small-ad for as little as £20. Please contact Ray Goddard at Head Office on 0118 939 1537 for more details. Advertisements received before 23rd May 2008 will be considered for inclusion in the next issue of Tidings.

Open Days

Colorectal and stoma care nurses from the following hospitals are holding Open Days during April and May

Manchester Royal Infirmary
Date: Tues 15th April 2008.
Time: 11am – 3pm.
Venue: The Postgraduate Centre
Manchester Royal Infirmary.

Countess of Chester Hospital
Date: Wed 23rd April 2008.
Time: 1.30pm – 5.30pm.
Venue: Freemasons Hall
Cheshire View, Plough Lane
Christleton, Chester.

Southend University Hospital
Date: Thurs 24th April 2008.
Time: 9.30am – 3.30pm.
Venue: Essex County Hotel
Aviation Way, Southend on Sea.

St Peter's Hospital
Date: Mon 28th April 2008.
Time: 4pm.
Venue: Postgraduate Education
Centre, St. Peter's Hospital
Guilford Road, Chertsey.

Salisbury District Hospital
Date: Wed 7th May 2008.
Time: 2pm – 5pm.
Venue: Guildhall
Market Square, Salisbury.

United Lincolnshire Hospitals
Date: Thurs 8th May 2008.
Time: 10am – 3pm.
Venue: Lincoln Drill Hall
Freeschool Lane, Lincoln.

Chesterfield Royal Hospital
Date: Fri 9th May 2008.
Time: 10am – 2pm.
Venue: Winding Wheel
Holywell Street, Chesterfield.

Essex Rivers NHS Trust
Date: Sat 17th May 2008.
Time: 10am – 3pm.
Venue: Moot Hall, Town Hall
Colchester.

Stoma Care Open Days organised by nurses working within the NHS, where several manufacturers and suppliers are represented, will be included on this page free of charge.
For a complete list of forthcoming Open Days visit our website www.colostomyassociation.org.uk and click on events.

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Tidings

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Support Group in the Spotlight

Inside Out Stoma Support group

INSIDE OUT

In November 1999, Celia Myers, who at the time was head of the Stoma Care Dept at St Mark's Hospital, asked Clare Bossom, Community Stoma Care Nurse for Harrow and myself to come in to see her. After a long discussion it was decided that we could best help the community by setting up a support group to deal with all forms of stomas (colostomy, ileostomy, and urostomy) rather than just concentrating on one stoma.

Since we set up the group, we have helped a number of people come to terms with their stomas and guided them and their families so that they maintain a quality of life even though their life may have been turned on its head. They are informed they have cancer, Crohn's disease or colitis and after trying everything else there is no other alternative but to have a stoma. This is when our group comes into action. We have befrienders who, if they are needed – not always as some people deal with it their own way - support the patient and his/her family. They help them to understand what is happening, answer the non-medical questions, are there for them in the beginning when they have the operation and follow them up afterwards. They are there as a form of life line to deal with any non-medical problems.

This has worked very well and we have helped many ostomates over the years. We hold coffee mornings every two weeks in the out-patients department, level 3 of St Mark's Hospital. The days change as we cover a number of consultants both in the medical and surgical departments. We also hold Open / Information Days at St Mark's once a year in June, when we invite the manufacturers to come along. Ostomates can come and look at what is new, talk to other ostomates and hear the speakers talk about new developments.

We became part of St Mark's Hospital Foundation, in 2004, so that we could achieve charity status without creating another charity and the arrangement has been helpful to both parties. For us, because we have the clout that we would not have gained in our own right and for St Mark's because they have the patient care side.

We produce a newsletter every three months. We post it out to our members, who exceed two hundred, and distribute the rest around the hospital. In it there are very informative articles, written by leading consultants, plus many other titbits of information to help all ostomates. We have a very large data base of information which can be either posted or sent via email or from our website www.iossg.org.uk
If you wish to find out more about us then you can contact me, Bob, on 020 8428 4242.

Robert Azevedo-Gilbert
Chairman.

This year Inside Out is holding their Open Day & AGM on Saturday 7th June at St Mark's Hospital (Level 6, Himworth Hall).

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

Tidings
Dedicated to Colostomates and their Carers

News of local stoma support groups...

B.O.S.S. (Bristol Ostomy Self Support) will meet at The Pip n' Jay Church Hall, Tower Hill, Bristol BS2 OET at 2pm on:
Saturday 7th June 2008
Saturday 27th September 2008
There will also be a meeting on Saturday 6th December – venue to be decided.

For further details contact Christina 0117 9075326 or Joyce 0117 9558236

Optomists, the Cornwall Ostomy Support Group, meets at the Headquarters of the Cornwall Women's Institute, Three Milestone, Truro Business Park, TR4 9NH, usually on the first Monday of the month from 2pm till 4pm.

Dates of next meetings:
12th May 2008.
2nd June 2008
7th July 2008.
For further details contact Sue Hatton 01326 340058

Oldham Stoma Support meets quarterly at Links Centre, Union Street, Oldham from 7pm to 9pm.

Dates of next meetings:
3rd June 2008
2nd September 2008
2nd December 2008
For further details contact June Wilde 0161 6787086

New Groups

Southampton Support Group
You may remember in the last issue of Tidings we mentioned that Carole Summer was setting up a support group in Southampton. Several of our readers living in the SO area contacted Carole and the first meeting was held in March.

Future meetings are going to be held: on the last Wednesday of every month at Kings Community Church, Upper Northam Close, Hedge End Southampton SO30 4BB

For further details contact Carole 02380 446779.

Do you live in South Derbyshire?
A Stoma Support Group held its first meeting at The Old Post Centre, Newhall, Swadlincote on 8th March. A stoma care nurse was present to answer ostomate's questions. It is hoped to hold future meetings on the second Saturday of every month from 10am until 12 noon.

For further details contact Anne on 01283 214389

If you contact us before 23rd May 2008 we will publish the date and venue of your next Stoma Support Group meeting.

For a complete list of Support Groups in the UK visit the CA website www.colostomyassociation.org.uk and click on Support.

Is there no support group in your area? Are YOU interested in setting one up?
If so let us know at head office and we will provide help and advice. We can also put you in touch with other ostomates who have set up their own local groups.

Fundraising...we need your help

Everyclick raises £210.79

Since registering with Everyclick the Colostomy Association has raised £210.79. It's a great way to give and costs you absolutely nothing. If you register with www.everyclick.com as your homepage then we receive a donation every time you search the web. Everyclick.com works just like any other search engine, but allows you to choose the Colostomy Association as a charity you would like to benefit from your searches. The revenue generated for us comes from the companies that advertise on the site. There is no sign up fee or hidden charges to you or us; it's free giving.

£393.84 from Redeem recycling

Last year we received £393.84 from Redeem recycling. If you have an old mobile phone or ink cartridges (not Epson) then let us know and we will send you a freepost envelope. Alternatively log on to www.recyclingappeal.com for more information.

500 Club

Thank you to all of those who have applied to become members of our 500 Club.
If you have applied and have not yet received a confirmation letter advising you of your club number, please contact the office (0118 939 1537).
We still have some spaces left so it is not too late to apply. Either complete the form from the last edition of Tidings or contact the office and we will send you one.

The first draw will take place at the end of June but remember – you have to be in it to win it!

These fundraisers are an important source of income to us as we rely solely on donations to continue our work of giving support to colostomates.

Tell us more about your fundraising events... for CA


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- For further information and to obtain an Order Form Freephone : 0800 389 3111

Security and Leakage Belt

- The Security and Leakage Belt is made of a soft 32mm (1.25") elastic belt attached to a retaining flange that fits between the bag and the adhesive section of the pouch.

"the ring of confidence"

- This lightweight unobtrusive belt is designed to help eliminate leakage problems by holding the adhesive section of the pouch against the body during all activities.
- The belt also gives added security against the pouch becoming detached and will help to support the weight of a full pouch

Ref. no. SR103

Sash Medical Limited
"Woodhouse", Woodside Road, Hockley, Essex, SS5 4RU.

Stoma Support and Hernia Belt

- The Stoma Support and Hernia Belt is made of a 50mm (2") non elasticized webbing attached to a restraining flange that fits between the bag and the adhesive section of the pouch.
- The SASH Stoma Support and Hernia belt is designed and manufactured by an Ostomist and gives support to the muscles surrounding the stoma.
- Eliminates most leakage problems and gives added security and confidence. Ostomists report relief from dull aches and pain in the stoma region while wearing the belt.
- Used by ostomists with a pasastomal hernia (a bulging around the stoma) the belt will also help prevent muscle damage and enlargement of the hernia.
- Ideal for work, sports, gardening, housework, DIY or at any time stomach muscles require a firm support.
- With support from the Sash belt and periodic consultations with a consultant some Ostomists are delaying, maybe permanently, the need for hernia surgery.

Ref. no. S1

Freephone 0800 389 3111
Website:- www.sashstomabelts.com

SASH stoma support and parastomal hernia belts are suitable for Colostomy, Ileostomy, Urostomy, Umbilical and waistline Insisional hernias. The SASH stoma hernia belt has been designed and developed by an ostomist to give support to a hernia that surrounds the stoma without restricting normal body movement or limiting muscle use.

For more information:
SASH Woodhouse Woodside Road Hockley Essex, SS5 4RU England
Telephone: 0044 (0) 1702 206502 Fax: 0044 (0) 1702 206502 Freephone: 0800 389 3111
E-mail address: info@sashstomabelts.com Website: www.sashstomabelts.com

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)

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

Donations & Standing Order Authority

colostomy association

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: C.A. 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 would like the tax to be reclaimed on any eligible donations that I have ever made or will make to the Colostomy Association until further notice.

giftaid it

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

Signed: Date:

Upfront

Do you have any ostomy supplies that you no longer need?

There are organisations which send stoma pouches to countries where it is difficult or impossible to obtain modern, reliable appliances.

Jacob's Well Appeal is a charity which supplies humanitarian aid to Eastern Europe and Asia. One of its many projects is to collect medical supplies including stoma appliances and send them to these countries. To save postage costs remove any excess packaging and boxes – just put the pouches in a plastic bag, parcel them up and post them to the address below.

Jacob's Well Appeal
2 Ladygate Beverley
East Yorkshire HU17 8BH
Reg. Charity No. 515235
Tel:01482 881162
e-mail TheJacobsWell@aol.com

S.C.A.R (Stoma Care And Recovery) is a support group for people with stomas and for several years they have been sending surplus ostomy supplies to other countries. Although it is becoming more difficult to get the parcels transported abroad they are still collecting and are extremely grateful to all those who have helped. Any appliances you are unable to use can be sent to the address below (check first by phone or e-mail).

Maggie Littlejohn
1B Redburn Gate Kilwinning Road
Irvine KA12 8TH
Tel 078177 36147
e-mail maggielittlejohn@aol.com

Going on holiday?
Looking for travel insurance?

Why not try the Colostomy Association Travel Insurance Policy (C.A.T.I.P.)

Visit our website:
www.colostomyassociation.org.uk
and click on travel insurance on the left hand side of the home page for more information and a quotation.

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, article, letter or any other item you would like to be included, please post them to The Editor. Alternatively e-mail to our contact details below. We look forward to hearing from you and will do our best to include your contributions.

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

Visit our 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
- IOA International Ostomy Association
  www.ostomyinternational.org
- Gay Ostomates
  Tel: 0844 414 2356
  e-mail info@gayostomates.org
  www.gayostomates.org

Support Organisations for medical conditions...

- Macmillan Cancer Support
  Freephone:
  CancerLine: 0808 808 2020
  YouthLine: 0808 808 0800
  www.macmillan.org.uk
- Cancerbackup
  Freephone: 0808 800 1234
  www.cancerbackup.org.uk

Although Macmillan Cancer Support and Cancerbackup are merging all telephone numbers and websites remain the same at the present time.

- National Association for Colitis and Crohn's disease
  Tel: 0845 130 2233
  www.nacc.org.uk
- The Gut Trust
  (Irritable bowel syndrome)
  Tel: 0114 272 3253
  www.theguttrust.org
- Incontact
  (Incontinence & Diverticular disease)
  Tel: 01536 533233
  Web: www.incontact.org

RADAR
the disability network

NATIONAL KEY SCHEME

How to obtain a key to gain access to toilets for the disabled

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.

Keys can be obtained from the Colostomy Association at cost of £3.50. Contact head office: 0800 328 4257 for an application form.

Keys can also be purchased for £3.50 from RADAR:
Tel: 020 7250 3222
www radar-shop.org.uk

RADAR also publish a guide which lists all the NKS toilets throughout the UK (cost £10.25).