

# Tidings

*Dedicated to Colostomates and their Carers*

A moment  
to Celebrate...



## An amazing day...An incredible year



### Welcome...

I don't think there can be any one of us who didn't question why they had to have a colostomy and why they had to live the rest of their lives with their stoma.

On Wednesday 15th November, I stood, with the other Trustees, to give my speech of thanks to everyone who had come to help us celebrate our first year of being the Colostomy Association. I knew then that there was a reason for 'Bertha', my bag, and my nine year journey through Cancer and living with a Colostomy! I felt so incredibly proud to be part of this very special group of colostomates.

It was an amazing day. First we had a great Trustees meeting. In 2005 Macmillan withdrew its funding and we were forced to become a totally self sufficient, self funded charity. At the time those of us who volunteered to be Trustees never imagined that we would be so successful a year later. We all had the confidence and the passion to know how vital the Colostomy Association was to so many people and we were determined to make it viable.

It has been a difficult year financially, but we have successfully raised funds and received wonderful support from members and suppliers. Nevertheless the organisation still exists on a hand-to-mouth basis.

There have been so many challenges and obstacles to overcome, and a lot of hard work by the Trustees, but we have great respect for each other and, ultimately, we have made a dream come true.

In my speech at the Birthday Celebrations I had a tremendous list of people to thank including Celia Waters for having the vision to take the Colostomy Association forward. Most importantly, the Trustees would like to extend a special thank you to our Trustee and Treasurer, Ray Goddard.

Ray is married to Beryl, who works in the CA Office. They live in Frimley, a stones throw from our offices in Reading. Many of you will have spoken to Beryl on the helpline. She has had a Colostomy since the

age of five, so knows more about life with a Colostomy than most of us. Ray has worked with the National Westminster and Royal Bank of Scotland for thirty-two years.

He became a Trustee to help with the financial side but realised how much more he could do. When Celia left, Ray agreed to run our office, on a voluntary basis, and he has, with the support of Gill and Jo, turned it around gently and smoothly to become a happy, industrious base for the CA. He has forged great ties with other organisations, manufacturers, the National Health Service and all of our volunteers and "friends". We are indebted to him for being such a determined, resolute, guiding hand over the last year. Ray will remain as our Trustee Treasurer but will now also become our salaried Office Manager.



Ray and Beryl Goddard

In 2006 we saw the Colostomy Association:

- represented throughout the country by volunteers furthering the new association.
- continue to monitor the NHS changes with volunteers representing the members on committees and working parties.
- take members complaints to the British Airport Authority about the issue of stoma supplies in hand baggage and to the BBC about a derogatory remark on the programme Newsnight.

In 2007 we plan:

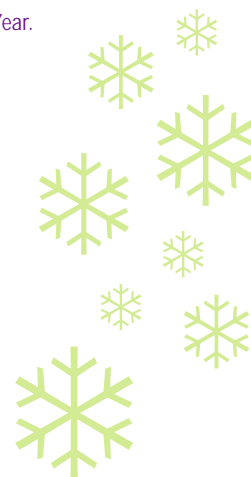
- to see a professional, user friendly website for the CA with links to other websites and advertisers.
- to continue the challenge of recruiting and training more volunteers.
- to act as a conduit for patients' concerns about their appliances, to inform the manufacturers and expect results.
- to raise awareness of bowel disease, the benefits of a stoma, temporary or permanent, and the importance of the inclusion of stoma care in nursing training.

The New Years Resolution of the Trustees and staff of the Colostomy Association will be to continue to listen to your concerns and to work very hard on your behalf.

The Trustees and office staff would like to thank you all for believing in us and supporting us. On their behalf, I wish you all a very Happy New Year.

*Sue*

Sue Hatton  
Chairman of the Trustees



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## Editorial Team

Rosemary Brierley (Editor)  
Colostomate & Helpline Volunteer

Jackie Dudley  
Colostomate & Volunteer

Beryl Goddard  
Colostomate & Office Helpline  
and Support Group Administrator

Gill Herbert  
Office Administrator

Ernie Hulme  
Colostomate &  
Vice Chairman of Trustees

Jo McKenzie  
Office Administrator

## Design & Production

Jane Wood - Senior Partner  
Art Direct Design Partners  
Art Direction, Design & Production

John Townsend - Account Manager  
Lampert Gilbert Limited



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.

Freephone: 0800 587 6744 or 0800 328 4257

For any editorial, telephone or  
advertising queries contact: 0118 939 1537

Office Address: 15 Station Road  
Reading RG1 1LG  
Tel: 0118 939 1537 Fax: 0118 956 9095  
E-mail: [cass@colostomyassociation.org.uk](mailto:cass@colostomyassociation.org.uk)  
Web: [www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk)

The views expressed by the contributors are not necessarily those of the Colostomy Association. Great care has been taken to ensure accuracy, but the Colostomy Association cannot accept responsibility for errors or omissions.

The Colostomy Association does not dispense prescriptions, stock Stoma care supplies or do home deliveries. We show no partiality to any manufacturer or supply company. We do not sponsor Stoma Care or Colorectal Nurses.

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## Dear Readers..

Earlier this year I was invited to join the editorial team of Tidings. I am delighted to have now been asked to become the new editor. It is a pleasure to read the many letters and articles we receive. As a colostomate myself, I will try to make sure that we address the issues which are important to you.

After announcing that the theme this time would be colostomy irrigation, many of you contacted us about this subject and your contributions appear in the centre pages. Our thanks also go to the Stoma Care Nurses at the Buckinghamshire Hospitals who have provided a very informative article on this topic. We do realise that the majority of our readers do not use this form of colostomy management and hope that after reading these articles some of you will decide to contact your stoma care nurse and give it a try.

We also accept that some colostomates are unable to irrigate or do not feel the need to do so. We hope that you will still be able to identify with some of the sentiments expressed by our "irrigators" and, in this "bumper" forty-eight page Tidings, there are other items which you will find of interest.

In this issue, there is also an article by a Consultant and a Specialist Nurse at the Pelican Centre, colostomates write of their experiences of phantom rectal pain and of using the plug as an alternative means of stoma management. We also report on a support group's pledge to ensure they don't over-order appliances and accessories, and air the views of our readers on the disposal of used pouches.

Summer holidays may seem a long way off, but we are always thinking ahead. In the Spring Tidings we are planning to include information on travel. We would like to hear of your experiences with insurance companies in the last year or so: Did you get a good deal? How long a time period did your policy cover? What was your destination - Europe or further afield?

Thank you to everyone who returned their questionnaire; we will do our best to include what you like to read. Keep your articles and letters coming in - these are what makes Tidings your magazine.

Happy New Year and Best wishes,

*Rosemary*

Rosemary Brierley  
Editor

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

# Colostomy Association's First Birthday Celebrations...

Our first birthday celebration took place at Station Road on the evening of 15th November. A number of manufacturers and supply companies had displays and approx 50 guests, including trustees, volunteers and local members attended. A special mention must go to two of our intrepid volunteers, Mollie Thompson and Barbara Orlans who travelled from Scotland and Liverpool to be with us. Sue Hatton made a speech thanking everybody who had supported us through our first year followed by the raffle draw by Glyn Davies A.M. for Wales.

*“...It has certainly been an eventful, but exciting, year for all of us and we are all proud that we have made it through to this, the first anniversary of the Colostomy Association coming into being. We have some very ambitious and exciting plans for next year including the further development of our new website and we have every intention of going from strength to strength...”*

*Extract from Sue's speech*

## The trustees of the Colostomy Association would like to thank the following...

- Celia Waters, for making sure that support to colostomates did not disappear with the demise of the B.C.A. and for seeing us through the first six months of the year before jetting off to Dubai with her family.
- Jo McKenzie and Gill Herbert for sticking with us through the year. Through sometimes turbulent times they have remained focused on providing support to our members.
- Beryl Goddard and Jackie Dudley for manning the Helpline in office hours and for their energy and enthusiasm in turning their hands to anything that needed doing.
- All the manufacturers and suppliers who have supported us over the first year with a specific mention to the CliniMed group of companies for signing up to our platinum scheme and providing us with a welcome boost of income when it was most needed.
- Art Direct Design Partners, Lamport Gilbert Printers Ltd and McMillan-Scott for all of the hard work they have put in to ensure that our Tidings magazine continued to hit the doormats every quarter.
- Macmillan Cancer Support for letting us remain at Station Road and for donating the office equipment, reducing our rent and passing on to us funds which were being received into the B.C.A. account.

Lamport  
— Gilbert

mcmillan-scott

WE ARE  
MACMILLAN.  
CANCER SUPPORT



Celia Waters with two volunteers



L to R: Jo McKenzie and Gill Herbert



L to R: Beryl Goddard and Jackie Dudley



CliniMed Group HQ



Jane & Mike - Art Direct Design Partners



Our Volunteers - the frontline of the CA



# *Glyn Davies AM/AC has become a valued friend of the Association and took time out from his busy schedule to join in with our Birthday Celebrations...*

*The raffle was drawn by Glyn Davies AM/AC Conservative Assembly Member for Mid and West Wales. Aelod o'r Cynulliad trios y Ceidwadwyr Canolbarth a Gorllewin Cymru.*

Some of our readers may recall an article in our December 2004 issue of Tidings, where Glyn shared his experience of being diagnosed with colorectal cancer and learning to live with a colostomy. In 2006 he wrote stressing the importance of screening programs for bowel cancer and calling for priority to be given to the testing and approval of new drugs and their availability to all who would benefit.

I first met Glyn back in the winter of 2002/03. Upon arriving at his Farm in Berriew Mid Wales I was greeted by his wife, Bobbie, only to be told that he was down in the town talking to the Firemen - if I remember correctly there was some sort of dispute on around this time. Having had treatment and major surgery fairly recently, it was obvious this lad was not going to be caught dragging his heels. After Bobbie plied me with tea, I took the opportunity to take a sneak preview at one of Glyn's great passions, his garden. Even in the depths of winter his pride and joy was outstanding: at every turn you could see the attention to detail that only a passionate gardener makes.

Born into farming in 1944, Glyn went to Castle Caereinion Primary then on to Llanfair Caereinion High School, which he left at 16 because of his Da's serious illness. He spent his early working years running the family farm. Glyn married Bobbie in 1966, three years before Neil Armstrong walked on the moon and six years after the Beatles first sang together. Their marriage has been blessed with four children.

At the age of fifty Glyn attended Aberystwyth University where he gained a diploma in International Law and Politics. I was still at school when Glyn married (I

had to get that one in!) and, unlike me, he has maintained a high level of fitness that's sees him still playing the odd game of rugby - but what do the Welsh lads know about rugby? Being physically active stood him well for his surgery, his fitness preparations saw him recover in double quick time. He set himself a list of objectives and goals which were not dissimilar to what most new ostomates wish to achieve - a return to his previous lifestyle.

Nearly all of us get back to where we were before and I will always remember talking to a grand lady with a new stoma who said, "I read about people like us climbing mountains and doing fantastic things, but I just want to be me again."

Glyn has certainly resumed his previous lifestyle but with an added qualification, his personal experience of cancer and his stoma. He has become a valued friend of the Colostomy Association and champions the cause of all cancer sufferers at every opportunity, both inside the Welsh Assembly and outside.

We read so much adverse publicity about politicians, but how many would take time out of their busy schedule to travel over a hundred miles at the end of their working day to spend a couple of hours drawing a raffle then return the same way. The people of Mid and West Wales are fortunate and can be assured of good representation in the Welsh Assembly and us pouchies at the Colostomy Association have a very good friend in Glyn Davies, even though he does have a strange accent, unlike "may up ere in't Potteries."

*Cheers Glyn*

*Ernie Hulme*



*"...Glyn has certainly resumed his previous lifestyle but with an added qualification, his personal experience of cancer and his stoma. He has become a valued friend of the Colostomy Association and champions the cause of all cancer sufferers at every opportunity, both inside the Welsh Assembly and outside..."*



## Fundraising...making a difference

*Fundraising plays a vital role in the CA and we welcome your comments and ideas. All efforts are greatly appreciated. Fundraising can be hard work, but keep it simple, accept offers of help and above all - enjoy yourself!*

### Great North Run

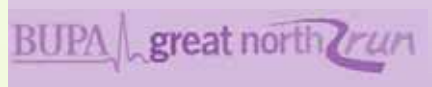
Many thanks to Paul Gotts who completed the BUPA Great North Run on our behalf. He raised a staggering £1,298 which is our biggest single donation to date. Even better, the whole amount is eligible for gift aid.

*A huge thank you and well done to Paul from all at the Colostomy Association.*



*Paul Gotts  
raises a  
staggering*

**£1,298**



### Raffle Update...

With money still coming in we are on target to raise more than £5000.

*A huge thank you to all*

### Legacies

Charities such as the Colostomy Association are heavily dependant upon donations to enable us to continue to provide our services. Leaving a donation in your will to the charities that you support may be something that you might like to consider. Twenty percent of people in the U.K. die without having made a will and this often leaves loved ones to face complicated legal and financial matters at a distressing time. Making a legacy, in favour of the Colostomy Association, is a straightforward, easy and cost effective way to support our work. It involves adding a clause to your will or, if you already have one, the addition of a codicil. You will need to consult your solicitor in both cases to ensure that you do not invalidate your will.

Many people believe that a legacy has to be a large sum of money. This is not so. Any sum of money, or gift, left in a will is important to us. Many people leave a fixed sum or a proportion of their estate as a legacy to a charity. This could impact on inheritance tax.

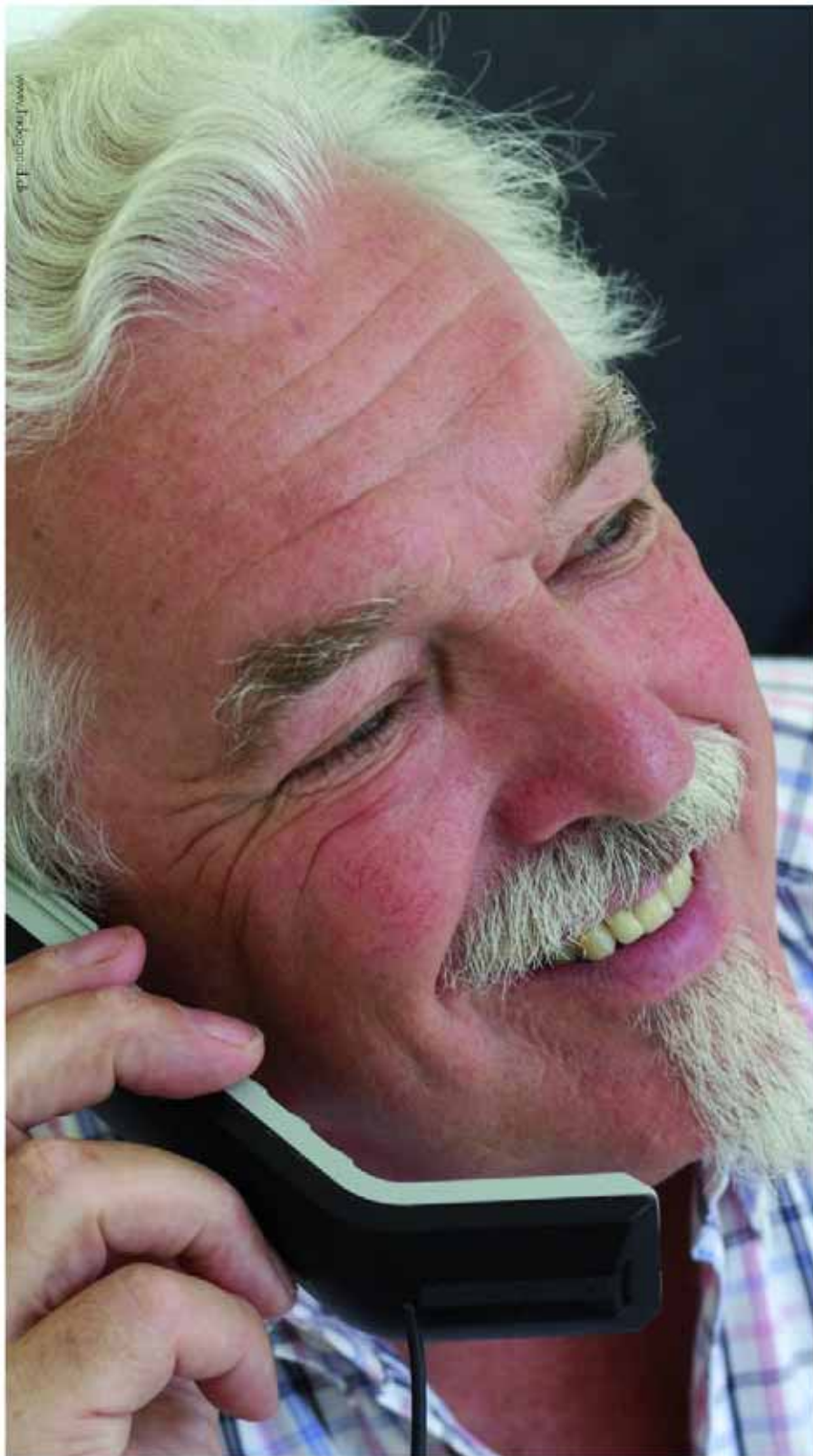
Legacies are an important source of funds for charities. Some of the larger charities, such as Macmillan Cancer Support, receive up to a third of their income from legacies. So, if you are about to make a will, or are considering making a change to your current will, spare a thought for the Colostomy Association and consider making a legacy to help us to continue to support Colostomates country wide.

### CONGRATULATIONS TO ALL!

1st PRIZE Holiday in Cornwall Winner: Jean Wilson	Ticket No: 4859
2nd PRIZE £250 M&S Vouchers Sue Hatton	Ticket No: 6683
3rd PRIZE Overnight stay at Lowndes Hotel, Belgravia, London Winner: T. Brierley	Ticket No: 0877
4th PRIZE Afternoon tea at the Dorchester Winner: Paulette Morin	Ticket No: 0383
5th PRIZE £75 WH Smith Voucher Winner: McManus Family	Ticket No: 6400
6th PRIZE DVD Player Winner: Diane Everett	Ticket No: 1224
7th PRIZE Encarta 2006 Winner: Jackie Dudley	Ticket No: 3266
8th PRIZE £20 Game voucher Winner: Alison Hall	Ticket No: 4585
9th PRIZE Vue Cinema Vouchers x4 Winner: D. Kilner	Ticket No: 4335
10th PRIZE Risk board game Star Wars edition Winner: S. Bryan	Ticket No: 4404
11th PRIZE Autoroute 2006 Winner: Helen Oakey	Ticket No: 5820
12th PRIZE Microsoft Office Professional 2003 Winner: W. J Liddle	Ticket No: 2216
13th PRIZE £10 B&Q Voucher Winner: Trafford Bowel Cancer Support Group	Ticket No: 4279
14th PRIZE £10 M&S Voucher Winner: Denise Williams	Ticket No: 6392
15th PRIZE "School Days to Spitfire" By Dr Gordon Mitchell Winner: V. Dunbar	Ticket No: 3228

**A RAFFLE WITH A DIFFERENCE...**





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## Advanced Colorectal Cancer Research and Assessing Quality of Life

Sarah Fisher RGN & Ian Daniels FRCS ~ The Pelican Cancer Foundation

The Pelican Cancer Foundation is a registered charity in Basingstoke, founded in 2000. It is based on the pioneering work of Professor Bill Heald and the development of precision surgical techniques for rectal cancer. The aim of the charity's work is to improve survival and quality of life for patients with cancers of the liver and pelvis through research and the education and development of colorectal multidisciplinary teams (surgeons, specialist nurses, radiologists, oncologists and pathologists).

Pelican, which is based in the ARK, has delivered a national, government-funded initiative, commissioned by the National Cancer Director, Professor Mike Richards. The English National Multidisciplinary Total Mesorectal Excision Development Programme, launched in 2003, has provided education and the sharing of best practise for 180 colorectal multidisciplinary teams from the UK.



*The ARK*



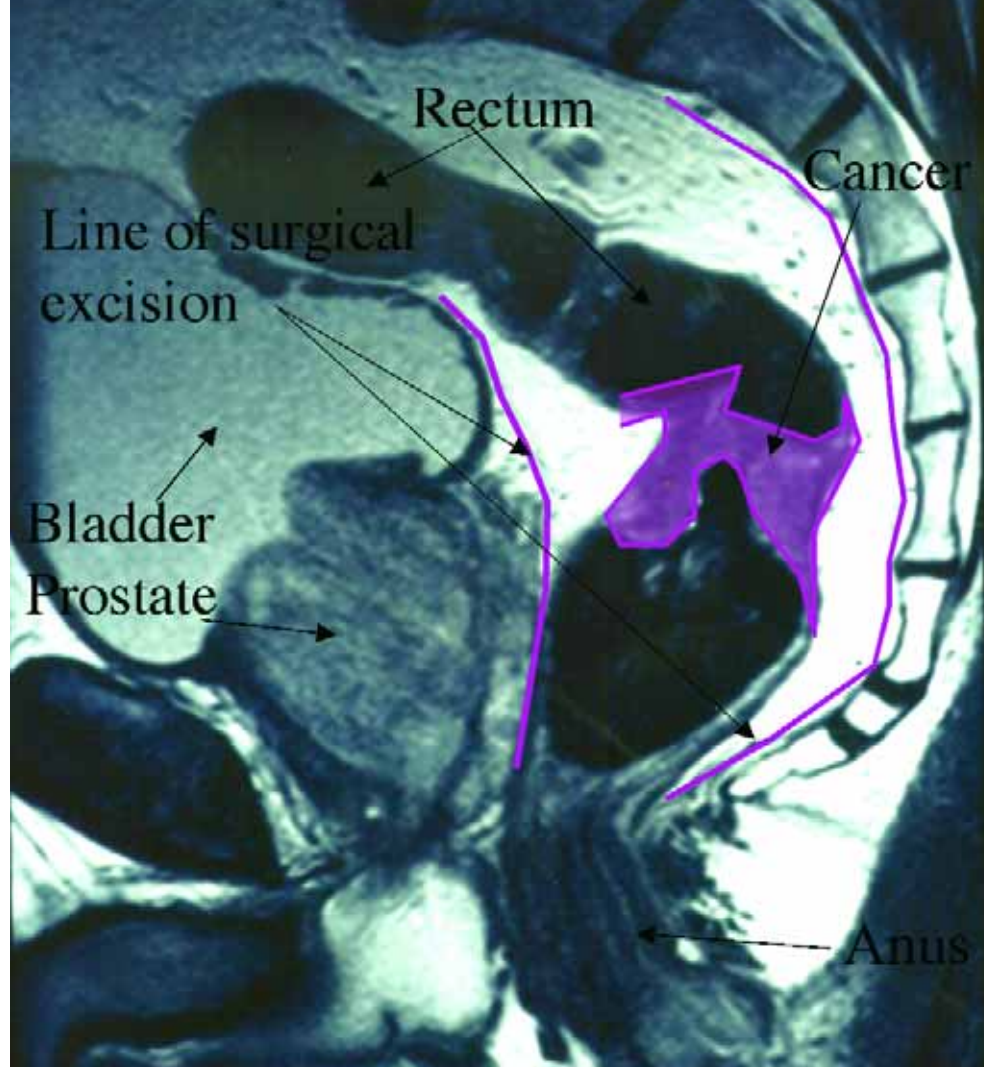
Research is also an important aspect of Pelican's work. We have recently published The MERCURY Study in The British Medical Journal (BMJ 14 October 2006). MERCURY was a European, multi-centre, multidisciplinary study, that aimed to assess the accuracy and effectiveness of using Magnetic Resonance Imaging (MRI) scans to predict the extent of a rectal cancer prior to surgery (see Figure 1).

The study, co-ordinated by Mr Ian Daniels FRCS and Ms Sarah Fisher RGN and involving twelve hospitals in four countries, has conclusively shown that important features of a rectal cancer can be seen, before surgery, on an MRI scan and that these features are the same as those found, following surgery, by the pathologist. This means that patients with early cancers may undergo surgery, avoiding unnecessary chemotherapy and radiotherapy. Those patients with



advanced cancers can be identified so that the multidisciplinary team (consisting of the surgeons, radiologists, pathologists, oncologists and specialist nurses), can plan appropriate pre-operative treatment, such as chemo-radiotherapy, to shrink the cancer and make curative surgery possible. This, we believe, will lead to lower rates of recurrent cancer in these patients and, ultimately improve overall survival. MERCURY proved that the specialised MRI technique was feasible and accurate in the hospitals that took part, and is now forming the cornerstone of 'individualised care' for patients with rectal cancer.

The MERCURY study highlighted the fact that further research is needed in the treatment of the very lowest rectal cancers (those within 6cm of the anus). Patients who undergo surgery for low cancers have more complications and face more quality of life issues than patients with cancers higher up in the bowel. This includes the need to remove the anus and therefore leave the patient with a permanent colostomy. Traditionally, quality of life and function in patients with cancer were considered secondary to cure and, the formation of a permanent stoma was perceived to be a failure in the ability of the surgeon and meant inferior quality of life for the patient. However, recent studies have challenged this view. With these issues in mind, the MERCURY team are now launching a new study with the aim of reducing the complications associated with low rectal cancer surgery and looking at quality of life, sexual, bowel and urinary function in patients who undergo such surgery. With advances in pre-operative MRI scanning, multidisciplinary team individualised patient management, pre-operative therapies and surgical



*Figure 1. An example of how the MRI scan is used to identify the cancer and the anatomy of the pelvis to allow the planning of treatment. The surgeon will excise the rectum by following the natural planes of cleavage between individual structures within the pelvis.*

techniques, the study will evaluate these changes and assess the benefits for patients. Whilst the rate of permanent stomas has fallen, the study may show that patients who receive support and counselling pre-operatively from colorectal specialist and stoma nurses and have a well functioning stoma actually have a better quality of life than patients who undergo sphincter-saving surgery and are then disillusioned with poor function. To collect the information we need, patients in our study will be asked to complete

detailed questionnaires, answering personal questions about bowel, urinary and sexual function.

Many of the advances in treatment for rectal cancer have come about from the results of clinical trials and studies. Participation in these studies is beneficial to both patients and clinicians and, if you or a loved one is facing cancer, participation in a clinical trial or study is an important treatment option to consider.

*If you would like further information about...*

*The Pelican Cancer Foundation and our research, please contact Sarah on 01256 313600 or email [s.fisher@pelicancancer.org](mailto:s.fisher@pelicancancer.org)*



## The British Red Cross

The British Red Cross helps people in times of crisis, wherever and wherever they are. It is part of a global voluntary network responding to conflicts, natural disasters and individual emergencies to enable vulnerable people in the UK and abroad to withstand emergencies in their own communities. When the crisis is over, they help them recover and move on with their lives.

But did you know that The British Red Cross also provides a range of services, delivered by skilled, trained volunteers and staff, to those most in need in local communities all over the UK? These services include...

### Home from Hospital Service -

This service provides help for people returning home after a stay in hospital. Volunteers assist in various ways: for example ensuring the house is warm and comfortable for the patient's return, going shopping or collecting prescriptions. For the ostomate this type of support can be invaluable in the first few weeks after stoma surgery.

### Other Support at Home -

Sometimes, after a fall or illness, or while their regular carer is away, people may require help in the home for a short period of time. Volunteers can visit and carry out a range of tasks such as preparing a meal or assisting with the daily routine.

Both these services aim to help people live independently and prevent the need for readmission to hospital.

### Transport and Escort Service -

This service is available to people who have difficulty getting out and about. A driver with a private car or specially adapted vehicle and, if required, an escort can be provided to make essential journeys possible. If it is a

problem getting to the hospital to visit your stoma care nurse, the Red Cross may be able to help.

To deliver these services effectively the Red Cross work in partnership with a range of organisations including GP surgeries, Primary Care Trusts, Social Service departments, NHS Trusts, local day centres and other voluntary organisations. As the Red Cross is a charity a donation is required, but not fundamental to receiving assistance.

### Medical Loan Service -

A range of equipment is available, on short term loan, from 1,000 outlets all over the UK. This scheme is to help people who are recovering from an accident, illness or simply looking to get on with their lives and maintain their independence.

The main types of equipment available include: wheelchairs, backrests, bath seats, commodes, bedpans and urinals, walking sticks and frames.

Equipment is usually available within 24 hours in an emergency and is loaned free of charge, although a refundable deposit may be requested. Donations from service users are welcome as they help to maintain this valuable service.

### Independent Living Products

"Ability" shops in Leicester and Goodmayes sell over 1,500 lines ranging from scooters to incontinence products. Over three hundred of these are available for purchase on line at the British Red Cross Shop [www.redcross.org.uk](http://www.redcross.org.uk). The sale of these products enables thousands of people to lead independent lives and helps to fund the British Red Cross.

Items on sale include chairs and leg rests that will make your home more comfortable and products like trays, trolleys and perching stools that will ease the strain of daily chores. For the bathroom there are grab-rails, bathmats etc. The mobility range includes walkers/shoppers, wheelchairs, crutches, walking sticks and frames.

For more information about any of these services:

Telephone: 0870 170 7000 to obtain details of your local Red Cross or alternatively visit [www.redcross.org.uk](http://www.redcross.org.uk):Independent living.



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# The Changing World of Stoma Care



*At a meeting of the Colostomy, Ileostomy and Urostomy Support Group in Nottingham, Shelley Biddles, Colorectal Nurse Specialist at the Queen's Medical Centre, outlines the changes proposed by the Department of Health Consultation document on the arrangement for the provision of Stoma Care Appliances. Members discuss what ostomates, themselves, can do to avoid incurring unnecessary costs and, hopefully, prevent these changes from being implemented. The group suggests a Stoma Patient Code of Practice.*

The first stoma nurses in Britain were appointed in 1969 and by 1978 The Department of Health was recommending that all health authorities should have at least one. Once referred to a specialist nurse, patients could, and still can, contact their nurse direct if they come up against problems. But all this could soon change. In future it may be necessary to first consult your GP and, if he feels it is necessary, he will refer you to a stoma care department.

Members of the group expressed their dismay at this news because, as we all know, each GP has only a few ostomates on his list and therefore does not come across stoma related problems very often – it is the colorectal nurse specialists and the

stoma care nurses who are the experts and can suggest the solutions. At present in Britain, stoma appliances are available on prescription and people with a permanent stoma are exempt from the current prescription charge. This is very different to what happens in other countries, where there is often a limit on the number of appliances to which ostomates are entitled. In Australia and New Zealand the allowance is one box of thirty bags per month. In the USA health insurance companies provide an annual lump sum to purchase ostomy supplies. This means that many colostomates irrigate and use the same appliance for several days. In this country the choice of which type of pouch to use is up to the patient – very important as we all differ and what suits one person does not necessarily suit another.

The consultation document also proposes generic pricing. The government will pay a fixed price depending on the type of stoma appliance. As well as reducing patient choice – not allowing ostomates to use the pouch they find most secure and most convenient – this will also mean that the manufacturers will have no funds for research and development. Over the last half century we have moved on from the

black rubber re-useable bag to modern day disposable pouches and even a toilet flushable version. Are we now to forego any progress to make our appliances more discreet and easier to use? Also let us not forget that a lot of stoma care nurses would not be in their NHS posts if it wasn't for the funding provided either directly or indirectly by the manufacturers of stoma appliances and the delivery companies.

Shelley, our nurse specialist, then opened the discussion up to the group, by firstly asking how much we thought a box of stoma pouches cost. The majority of us were aware that this could be up to a £100. This led on to a debate about whether there was anything we, as ostomates, could do to keep costs down. Shelley assured us that no one would expect us to go back to the days of re-using bags, but perhaps we could make sure we are economical, by ordering just what we need – not overstocking. "Stop being hamsters – Stop hoarding," someone suggested. But, as Shelley pointed out, this is not always the ostomates fault. In some cases supplies can build up, because when a patient leaves hospital a monthly prescription is arranged for an amount of bags, which in practice is more than he or she finds they need to use. The arrangement



continues because the patient is unwell and unable to change it. A manufacturer's representative at the meeting told us about how he received a call from a hospice. A patient had recently died and relatives had donated her surplus supplies. There were more boxes than he could fit in his car and the total value of the unused appliances was several thousand pounds.

Many delivery companies today offer a service whereby, when an ostomate needs further supplies, they telephone their helpline. The delivery company then contact that person's GP to request a prescription to be sent direct to the company who then deliver the supplies. This can be a valuable service to ostomates who are recovering from surgery or have mobility problems which make visits to the surgery difficult. However, it does have the disadvantage that the ostomate doesn't have the opportunity to check that they require all the items on the prescription. Often it is accessories i.e. adhesive removers, barrier creams, deodorant sprays etc. that the ostomate does not need everytime.

These all cost the NHS money, so it is important to let the delivery company (or doctor) know when they are not required. There are plans to take items off repeat prescriptions if they have not been requested for three months. Also the consultation document is recommending that delivery companies must have the prescription before they can send out supplies. If this is the case then all ostomates will have to ensure that they order their next batch of appliances in good time.

A delivery company representative pointed out that, although the envelopes they supply for sending in a prescription are Freepost and should travel First Class, sometimes they do take two days to arrive! He also reminded us that although, it is a good idea to allow extra time for delivery at Christmas, the warehouse is usually only closed for two days, so it is not necessary to order extra supplies.

## The Nottingham Colostomy, Ileostomy and Urostomy Support Group have developed the following Code of Practice...

### Code of Practice for Stoma Patients

- Don't overstock.
- Only ask for a prescription for the items you need.
- Always check your prescription to ensure it doesn't include un-requested items.
- Think ahead - Are your needs going to change i.e. if you are going to be having a course of radiotherapy would a drainable bag be more suitable?
- Check you are using the right product - A drainable bag is best if you have an ileostomy. If you have a fairly liquid output from your colostomy and need to change the bag more than two or three times a day, a drainable bag may be more appropriate.
- Don't order a whole box when all you need is just a few different bags - Maybe you are going on holiday and need a drainable version, just in case you get diarrhoea, or smaller pouches for swimming. Ring the manufacturer or delivery company and they will be happy to send a small supply of samples.

The Colostomy Association is actively involved in the ongoing consultation on the proposed changes within the NHS. We will be trying to ensure that all ostomates do not suffer a reduction in the services that they receive.



# The Disposal Debate...continues

*We have had a number of letters, phone calls and e-mails in response to Jackie Dudley's article on waste disposal. Here are some extracts with your opinions and comments. Also some suggestions which other colostomates may find useful.*



I was amazed to read that you had never heard of clinical waste collection. I have had a colostomy for thirty-five years and for the last twenty-five my used bags have been collected. So I say thank you Stoke City Council for the terrific service that I have received over the years.

B. R.

*The Colostomy Association has always been aware that some councils operate a clinical waste collection from private households. However, this service is not available in all areas. Below is an extract from a letter that one of our readers received from the Strategic Director for Environment and Transport at his local authority after he raised this issue with his MP.*



In normal circumstances the population is regarded as healthy or non-infectious and faecal waste of this nature would be classified as non-infectious unless a clinical waste assessment has indicated the presence of an infection such that an infection pathway exists. The advice I have received specifically regarding the correct way to dispose of colostomy bags suggests that the corner of the bag should be snipped off with scissors over the toilet pan and the contents flushed away. The empty bag should be double wrapped in plastic bags before disposal via the normal household refuse system. This is really no different to the disposal of nappies or incontinence pads.

Clinical waste collected in Portsmouth is transported many miles and disposed of in purpose built incinerators at high cost. It is not sustainable to dispose of normal non-infectious waste via this route. Locally any waste disposed of in the normal refuse collection process will undergo incineration and providing it is bagged appropriately the waste in question will not present any significant risk.

*The same reader also told us...*



My daughter manages a baby equipment shop and brought me a Sangeric twist and seal disposal system to try. These are designed for babies' nappies. Basically, there is a cassette of tubular polythene which fits in the top of the container. I put the used bag, wipes etc into a disposal bag, place this in the Sangeric container, then twist the top, to give a seal which prevents odour. At the end of each week, a device in the lid cuts off the polythene tube. I knot the end and everything is completely sealed, ready for disposal. Even in the hottest of weather I have not had any problem with odours at all. Using this method I can change my bag in less than 2 minutes. I have no connection with the company who produce Sangeric but I have found it a boon.

R.G.P.



I am one of those, who do not empty their bags before disposal, unless it is very liquid and will come out where it went in. When I had my stoma in April 2000, my stoma care nurse recommended that I buy a bin specially designed for babies' disposable nappies.

I put the used colostomy bag in a disposal bag provided by my supplier before putting it in the disposal bin, which then second wraps the bag. The special liners for the bin I purchase from my local supermarket and one pack lasts me about a month. The liners come in two sizes 0-4 months and plus 4 months. I find the 0-4 months suitable and they are the cheapest. I am still using the bin I purchased in 2000, so it has been good value for money.

I empty my bin once a week when the dustmen are due and have never had a problem with odour. My dustbin is normally collected weekly, but it can be fortnightly when we have a bank holiday.

J.D.

*Several other readers have also contacted the office to tell us about this bin designed specifically for the disposal of babies' nappies, incontinence pads and stoma products. It is on sale in most shops selling nursery equipment under the brand name of Tommee Tippee or can be obtained by mail order. More details available on [www.easiseal.com](http://www.easiseal.com)*



With all the hoo-ha in the press about the possibility of being charged by weight for the collection of household rubbish, I am wondering how this will affect myself and other colostomates. My reasoning is: if I don't have my waste going down the loo, will I get a rebate from the water company to offset any proposed charges for rubbish collection by weight? Pouches going into the grey bin would presumably add a significant cost to any proposed charges for household rubbish collection.

I do not relish the idea of having a clinical waste collection thereby telling all and sundry that I have a medical issue needing to be dealt with. I also know people who do use this service, which is apparently very unreliable and would be difficult to comply with as I work full time.

I wonder how other readers feel about this.

G.S.



I thought I would let you know of my disposal solution. I have a dog and every time I take her for a walk in the park, I take my used bag, suitably wrapped in a disposal bag, with me and drop it in the dog waste bin. These are emptied regularly and hygienically. I understand this may not be suitable for everyone, but it saves me having to dispose of it in the ordinary rubbish, as our council does not provide a clinical waste service to individuals.

F.C.





I had a colostomy in 2001 and the hospital stoma nurse showed me how to put on/take off my pouches. I got home with an array of samples of different 'makes' of pouch and the problem of disposing of used pouches – in hospital used pouches were whisked away as soon as they came off me.

I convalesced away from home. It wasn't possible to cut off the bottom of each pouch, empty and wash it out. Used pouches in their special 'blue bags' went into a plastic-bucket-with-a-lid. However, after a couple of days the smell became seriously embarrassing, meaning regular trips to the dustbin at the end of the garden.

The away-from-home District Nurse asked how I was coping with the colostomy. I said, 'Fine, except for getting rid of used pouches!' She then suggested flushable pouches.

Once home I contacted my stoma nurse who gave me some sample flushable pouches. Happily they suited my skin and, I have to say, as far as disposal goes, they've transformed my life. V.S.

*Lets hope that, in the not too distant future, all colostomy bags are toilet flushable. This would not only solve a major problem for all us ostomates, but also be more environmentally friendly.*



Having converted to the British designed and manufactured flushable bag long ago, the whole process is simplified and less, shall we say, "hands on". But a word of warning: flushables with a fairly bulky flange do not do at all well in ship or aircraft toilets, where vacuum suction is employed to whoosh the contents away. The answer is to cut the flange from the pouch with scissors, while wearing light rubber gloves. Also add a plastic cup or two of water to the contents of the bowl before pressing the swoosh button! It has never failed me yet.

J.E.

*A useful tip!*

## A new approach...and a warm welcome to all

Many of you will, hopefully, have already found our new website on your travels through the World Wide Web. For those who haven't, visit us at [www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk).

We have wanted a good informative website for some time and our design company, Art Direct Design Partners have worked with us to create a web presence that is welcoming, friendly and informative.

The website is still in development and will, eventually, have a wide range of information on support groups and open days as well as hints and tips and more general information related to stomas and stoma care. There will also be a forum page to enable you to exchange ideas and talk to other ostomates.

If you have any comments on the website, or suggestions for further pages, please contact us at Station Road.



A warm welcome to all

welcome • who are we • register • helpline • support • information • donate • forum

welcome

birthday celebrations

meet the trustees

how we are organised

mission statement

A warm welcome from the trustees of the

**colostomy association**

dedicated to colostomates and their carers

The Colostomy Association was set up in November 2005 to provide support, reassurance and practical information to anyone who may be about to have, or already has a colostomy. Appropriate support and advice is also provided to families and carers both before and after surgery.

This website is currently in the course of construction and we will eventually include details of Support Groups around the country, details of fundraising events, links to manufacturers websites, a discussion forum and information on a wide number of issues that could affect you in your everyday life.

Please return to this website as we will be adding new pages on a regular basis.

Colostomy Association Head Office: 15 Station Road Reading RG1 1LG  
Tel: 0118 939 1537 Fax: 0118 956 9095 Email: [cas@colostomyassociation.org.uk](mailto:cas@colostomyassociation.org.uk)  
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visit us soon at  
[www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk)

# Medicines and your Colostomy

## Are all types of medication suitable for ostomates?

The active ingredients in medicines taken by mouth are absorbed into the blood stream through the wall of the gut. Some tablets have a special coating which does not dissolve until it has passed into the latter part of the intestine. Ostomates may find that some tablets will pass out through the stoma before sufficient of the active ingredient has been absorbed. Colostomates who have had a significant amount of their intestine removed are therefore advised to avoid enteric coated or modified release tablets.

As the function of the colon is to absorb water, ostomates who have very little or no colon remaining can lose considerable amounts of fluid through the stoma. This can lead to dehydration and potassium loss. If a "water tablet" is required to treat fluid retention, a potassium sparing diuretic is advisable.

## Can medicines affect how a stoma works?

Some tablets and other drugs may affect the muscles and nerves which control the gut. An increase in the rate that food travels through the intestines can cause diarrhoea, while a slowing down can cause constipation. Some medication may also influence the amount of water absorbed from the colon, which can alter the consistency of the output from a stoma.

If you suspect that any medicines you are taking may be affecting the function of your stoma, first check the patient information leaflet to see if gastro-intestinal disturbances are among the listed side effects. However, do not stop taking the medication until you have discussed these concerns with your doctor. He will advise you on the best course of action and in most cases will be able to prescribe an alternative drug.

Consult your pharmacist about the most suitable non-prescription remedies. For example he will be aware of the different types of antacids to relieve heartburn – those that contain aluminium can cause constipation; brands containing magnesium are more likely to cause diarrhoea.

Iron supplements have been reported to cause loose stools and sore skin in some stoma patients. Other people have experienced constipation. It is common for the stomal output to turn black when taking iron tablets.

A side effect of many antibiotics is diarrhoea. As well as treating the infection for which they were prescribed, they also destroy the bacteria normally present in the large intestine. Some people find that probiotic yoghurts e.g. Yakult or Activia can help prevent and treat this side effect by restoring the balance of bacteria in the colon.

## Medications that may cause constipation

- Indigestion and heartburn remedies containing aluminium
- Pain killers, especially those containing codeine
- Tricyclic antidepressants e.g. Amitriptyline
- Drugs to relieve symptoms of Parkinson's disease
- Drugs to control epilepsy
- Calcium supplements
- Iron supplements

## Medications that may cause diarrhoea

- Indigestion and Heartburn remedies containing magnesium
- Antibiotics especially broad spectrum penicillins
- Iron supplements
- Some drugs for arthritis

The lists above are not all inclusive and drugs can affect individuals in different ways. The article is intended as a general guide only. Readers who experience alteration in stoma functioning or new symptoms are advised to seek medical advice.

References -  
British National Formulary,  
51, March 2006  
[corecharity.org.uk](http://corecharity.org.uk)

## Did you know?

Certain pharmacies offer a Medicine use Review. There is no charge for this service – it is funded through the NHS.

You can ask for this service if:-

- you have been getting your prescriptions at that particular pharmacy for three months or more.
- you regularly take more than one prescription medicine or you take medicines for a long term illness.

This meeting will be in a private area within the pharmacy. The pharmacist will answer any questions about your medicines and listen to any concerns you may have about taking them. An ideal opportunity to ask about your particular medicines and a colostomy.

For more information consult  
[www.dh.gov.uk/PublicationsAndStatistics](http://www.dh.gov.uk/PublicationsAndStatistics)



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# Colostomy Irrigation

In 2002 Tidings carried out a survey of its readers. Of the 2,800 colostomates who returned the questionnaire only just over 7% managed their colostomy with irrigation.

Irrigation is not an option for all colostomates, as some medical conditions or types of stoma mean that this process is not possible.

But why is it that only such a small proportion of colostomates, who could irrigate, choose to do so?

Is it because:

- We do not know that this option exists?
- We do not want to use this method?
- We have tried it and decided not to continue?
- Heavy workloads mean that stoma care nurses do not have the time to show us how?

## What is Irrigation?

Colostomy irrigation is a way of keeping the bowel clean by washing water through it every day or every other day.



### Stoma care nurses

- Explain why some patients are able to irrigate while others are not.
- Discuss the advantages and disadvantages.
- Describe the technique.

### Colostomates who irrigate

- Write about their experiences.
- Pass on hints to new irrigators or those considering using this alternative method of stoma management.





# Colostomy Irrigation

## Taking the mystery out of irrigation...

### Equipment needed:

#### To introduce water into the stoma:

- A plastic bag called a reservoir (see Fig.1) connected to a length of plastic tubing with a valve to regulate the flow. On the other end of the tube is a plastic cone which is inserted into the stoma.

#### To drain the water and faeces into the toilet:

- An irrigation sleeve, (see Fig.2) which is similar to a drainable stoma bag, but much longer.

The items opposite are available on prescription to colostomates when their doctor has confirmed that irrigation is possible and they have been taught the technique by a stoma care nurse.



Fig. 1 Water reservoir, tubing, flow clamp and cone

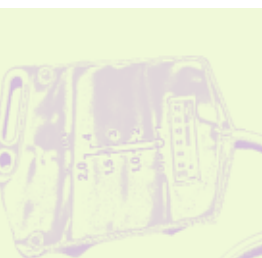


Fig. 2 Irrigation sleeve



# Irrigation explained

by Stoma Care Nurses, Andrea Thomas, RGN ENB and Clare Bossom, EN RGN 216  
SecuriCare Stoma Care Sisters - Buckingham Hospitals NHS Trust



Andrea Thomas  
RGN ENB



Clare Bossom  
EN RGN 216

Colostomy irrigation is a way of managing faecal output by cleansing the bowel.

It involves instilling a measured amount of water, using specialist equipment, into the bowel via the colostomy itself. The water then causes muscular contractions within the bowel, which in turn cause expulsion of its contents. Irrigation does not wash out the entire bowel but clears the lower (distal) colon of faeces.

The aim of irrigation is for colostomists to be in control of their faecal output so that faeces is only passed when the bowel is irrigated. Colostomy irrigation is a well established procedure that can be used by patients at home to achieve control over their bowel function and can improve their confidence and quality of life.

The most common way of managing a colostomy in the United Kingdom is through spontaneous action. There is no control over the bowel and people have to change their pouch usually twice per day. Many people find they have to control their diet. Certain foods can cause problems with wind, loose stools and odour. Laxatives may be required to regulate motions and some colostomists never develop a regular evacuation pattern. This can lead to a demoralising change to many aspects of a person's life.

The precise history of irrigation is unknown. The importance of 'regularity' and 'control' of bowel function can be traced back to ancient Egyptian times. The Egyptians associated faeces with decay so regularly used enemas to control their bowels. Early medical records have shown that in 1793 a French surgeon successfully washed out a child's stoma. Irrigation was introduced to UK surgeons in 1927 by Professor Lockhart-Mummery. Many doctors at this time feared colonic perforation with this technique so it was very limited in popularity.

Irrigation is not a popular procedure in the UK. In a study in 1989 it was found that only 4.7% of people with a colostomy had heard of irrigation. In 1999 it was found that only 2% of the 100,000 people with a colostomy were actually irrigating.

Irrigation is more common in America and other countries throughout the world. This could be due to the fact that stoma supplies are more expensive and not readily available. Also products may be inferior to those obtainable in the UK.

Stoma care nurses have the information and knowledge to introduce irrigation to their patients. They should inform suitable candidates about irrigation. The advantages and disadvantages should be discussed and a full explanation of all aspects of the procedure given so they can make an informed decision.

## Advantages

- Control is achieved over bowel function. Irrigation is performed at a time chosen by the person and between irrigations they are continent.
- A small appliance (stoma cap) or dressing is all that is needed to cover the colostomy. This can help with the anxiety caused by altered body image and give more confidence with appearance.
- A more varied diet can be enjoyed and the worry of wind, irregular motions and

constipation should be minimal.

- Disposal of used colostomy pouches is eliminated.
- Can stop problems associated with pouch leakage and allergy problems.
- There is far less equipment to store or carry around.
- Irrigation can be performed away from home.
- There is no age restriction - any age group can irrigate.

## Disadvantages

- It is time consuming and may need to be performed every day.
- The toilet or bathroom will be occupied for 45 - 60 minutes every 24 - 48 hours.
- It should be performed even if you are on holiday or away with work.
- Some people can view it as an unnatural procedure and distasteful to perform.
- Irrigation in the long term may possibly diminish the natural function of the bowel.
- If the incorrect technique is used damage to the bowel can occur.

## Who can Irrigate?

- You can irrigate if have an end colostomy situated in the lower part of your large bowel.
- Your motions should normally be semi formed or formed.
- You should have reasonable eye-sight and the use of your hands to be able to manage the procedure successfully. You will need to have the ability to make an informed choice about undertaking this procedure and be motivated and keen to succeed.
- Adequate bathroom facilities will be required at home allowing uninterrupted use of the toilet or bathroom for up to one hour each time irrigation is performed.

Your surgeon's consent must be gained prior to commencing irrigation as with some medical conditions irrigation is not advisable. Your GP should also be informed of your intention to use this method.

## Who cannot irrigate?

- People with complications such as a prolapse, stenosis or large hernias.
- People with further bowel disease e.g. Crohn's disease, diverticulitis etc.
- Irrigation may not be successful if you suffer from persistent diarrhoea.
- Patients receiving radiotherapy or chemotherapy.
- Young children who have difficulty sitting still for any length of time.
- People with renal or cardiac problems - fluid overload could occur during irrigation.





## Irrigation - Problems and Solutions

Problem	Solution
Difficulty inserting cone into stoma?	<ul style="list-style-type: none"> <li>- Make sure you are relaxed. Gently dilate your stoma with your finger to determine the direction of your bowel</li> <li>- The cone may need to change direction slightly</li> </ul>
The water does not empty freely into the bowel?	<ul style="list-style-type: none"> <li>- Too much water may be being used</li> <li>- You may be too tense and need to relax</li> <li>- The cone may be blocked with faeces so would need cleaning</li> </ul>
Stools passed between irrigation?	<ul style="list-style-type: none"> <li>- Can be common at first - your bowel needs to get used to the procedure</li> <li>- Less water may need to be used</li> <li>- Time between irrigations may need to be decreased</li> <li>- The irrigation procedure may have been rushed and some faeces could have remained in the bowel and not expelled, so more time could be required</li> </ul>
Pain during irrigation?	<ul style="list-style-type: none"> <li>- The water may be too hot or cold</li> <li>- Running the water too quickly will cause cramps and pain, so slow down</li> </ul>

Irrigation can be taught post operatively when the bowel has started to function. However, many people have more than enough to cope with, coming to terms with major surgery and most stoma care nurses prefer to wait two to three months so that the patient has had a period of recovery and adjustment.

Stoma care nurses should give a full in-depth explanation about the procedure prior to teaching the patient. Booklets and videos/DVDs about the procedure are available and it is sometimes helpful to talk to another person who irrigates.

Ideally this procedure should be taught at home. The stoma care nurse should visit the patient at home to determine if any adjustments need to be made. Usually all that is required is a hook above the toilet, from which the water reservoir can be hung.

The stoma care nurse will demonstrate the equipment and its use and teach the patient how to irrigate. Regular visits during the first week are vital to ensure the patient is irrigating safely and using the equipment correctly.

This procedure needs to be performed daily for the first fourteen days. During this time a conventional pouch will need to be worn in case of spillages between irrigations. It can then be performed on alternate days as long as no stool comes through the stoma.

It is advisable that the irrigation is performed when the toilet or bathroom is free for one hour. Having to rush could cause anxiety and the procedure to fail. Irrigation needs to be performed at the same time each day.

### Equipment Required

Irrigation equipment is available on prescription from various manufacturers. They all have the same basic components.

#### You will need:

1. Water reservoir
2. Tubing with flow clamp
3. A cone
4. Lubricating jelly
5. Irrigation sleeves and pegs
6. Disposal bags
7. Tissues
8. Brush for cleaning
9. New appliance or dressing to be worn and any accessories used

The water container should be clear enabling you to see the water level and the flow clamp should be easy to manoeuvre with one hand. The irrigation sleeve should give a secure seal around the stoma and be long enough to drop into the toilet. It can be trimmed if needed. One or two-piece sleeves are available. One-piece sleeves are intended for single use only. Once used, the irrigation equipment should be washed with warm soapy water, dried and stored until its next use. It should be replaced annually.

### The Irrigation Procedure

1. Connect the reservoir, tubing and cone together. Fill the reservoir with tepid (36 - 37°C) tap water and hang it on a hook. The hook should be at shoulder level.
2. Open the flow clamp to allow water through the tubing - this will expel air - and then turn the clamp off.
3. Fit the irrigation sleeve over the stoma and sit on the toilet so that the sleeve hangs into the bowl.

4. Lubricate the cone and insert it gently into the stoma following the direction of the bowel. Your stoma care nurse will help you with this at first.
5. Open the flow clamp and allow the water to run into the bowel slowly. This should take 10 - 15 minutes. Most people use 800mls - 1 litre but the amount can be variable, (500mls - 1.5litres). You will get to know by experience what the right amount is for you. Should you experience cramping or pain during this time turn off the water, massage your abdomen and wait a few minutes before restarting.
6. When the water has run in, remove the cone from your stoma. Use the pegs to close the top of the sleeve.
7. Water and stools will begin to flow into the irrigation sleeve. It can take up to 30 minutes to complete the evacuation. During this time you can read a magazine or book!
8. When all the water is expelled remove the sleeve, wash and dry around the stoma and replace your dressing or appliance.
9. Dispose of the sleeve in your usual way, wash and dry the equipment used and store until next time.

In general irrigation is a safe and effective method for achieving a continent bowel. It needs to be taught by a stoma care nurse and the correct procedure followed. It is not a procedure that suits everybody. However, if you suffer with persistent problems with your colostomy it may be the option for you. Irrigation can give a new sense of freedom and control to your life.



# Irrigation...Colostomates' Experiences



Gloria Hadfield...describes how, after seven years wearing a colostomy bag, she started to irrigate.

Vanity, pure and simple - That was what started me irrigating...

When my elder daughter and her partner set a wedding date I had had my stoma for nearly six years and managed it well throughout that time by using a small drainable bag and avoiding wearing tights – tight clothing caused too many leaks. At this time I was still teaching part-time and doing everything else I had always done – including aerobics. Oh, and eating everything I like to eat, too. That was my decision, to carry on as normal and deal with my stoma output as needed.

My bowel habit has never been regular – except when I had my rectal cancer and the change in bowel habit, for me, was to regular, daily movements. After surgery the irregularity returned and I quickly learned that I couldn't cope with closed bags. I tried, but all too often when I was all clean, changed and ready to leave the house my stoma would start performing – or in the middle of dinner I would have to go and change.

For many of us, when a colostomy is formed, it is the loss of control that is the major frustration and the hardest thing to come to terms with. It was for me. The drainable bag gave me more control since I didn't have to change away from home unless on holiday. I could get on with my daily life, visiting the toilet to empty my bag as and when necessary, not worrying about when my stoma might work and changing the bag every 2 days or so.

Now irrigating has added to the control I have. But back to the wedding. The date was set for November 2002 and my daughter said she wanted each of us, parents and friends and relatives, to wear whatever we felt happiest wearing.

The trouble was that I have a hernia which was, and is, getting slowly bigger. My 'bump' was becoming more obvious all the time, especially to me. When I saw her trying on wedding dresses and her sister trying on bridesmaid's outfits I really didn't want to let them down. They both looked so stunning and I knew I could not feel my best without concealing my 4-month bulge.

My surgeon gave permission and my stoma care nurse was quite happy to teach me to irrigate. Indeed, she was most generous with her time. We spent three separate afternoons in one week together, though I haven't kept to the method she showed me because it didn't work well for me. It was only after talking to another irrigator that I learned I could try different approaches and find out what does work best.

Nor do I keep to the same time of day to irrigate. It all depends what is going on in life. Often I irrigate after our evening meal. That's if we are at home, but if we are going out to eat I prefer to irrigate beforehand. Yet again, mornings work very well but irrigating in a morning can seem to take too much time out of the day. I get up too late. I'm not a morning person. And the process still takes up to an hour.





So has it changed my life? Yes, I think it has, but it took a long time to get the right approach sorted out. It seems that it is different for everyone and for the first three years – yes, three years – I muddled along, sometimes irrigating successfully and sometimes not and sometimes asking myself why I continued to try.

The answer was that when it did work well it was worth all the other times it didn't. I was so much more comfortable, even though I had not realised when still wearing my drainable bag just how uncomfortable I was much of the time.

The worst thing for me about having my stoma was having to get up in the night to attend to it. I've never been a morning person (I already said that, but it is true) and 4a.m. I just don't want to know, but quite often I had to.

So I sleep better and more comfortably and in any position. No more waking in extreme pain because I am lying on my stoma and wind can't escape. Does that happen to everyone, I wonder?

And I wear what I want to wear. No need to hunt for trousers with a pleated front and I'm getting back into wearing skirts (and tights!) more often. No more lacy knickers – it's control I want, to hold my hernia in well. I keep thinking of trying control top tights, but so far haven't done so.

Recently I have had very sore skin underneath the material cover of my bag. It's better now with prescribed cream and wearing a 'stoma cap' instead of a bag. At least I had that option, though a small closed bag with a good filter is my preference these days because it lasts the two full days between irrigations, whereas the filter in the stoma cap becomes ineffective much sooner. Irrigation washes out all the solid stuff, but I still emit gas from the stoma, usually after eating.

Sometimes I worry for an instant about how long I shall be able to go on irrigating. I recognise that there may come a time when it is no longer possible but I really don't want to stop.

I stopped for 2 weeks, though, when on a coach tour in America. I just didn't have the time without getting up at 5 a.m. and

the tour was exhausting! Luckily there was hardly time to eat, either! So I know I would cope if I couldn't irrigate, but I hope I can continue for a while yet.



In finishing...I should tell you that the wedding went well and I now have two beautiful granddaughters. I irrigate before any childminding sessions so I do not have to think about my stoma. Nappies are enough to cope with on those busy days! And bottles. But it's lovely to be a doting Grandma... Even a vain one.

### **Beryl Goddard - our Support Group Co-ordinator tells us how irrigation changed her life.**

I am sure some of you will think, not Beryl again! but, as you now know, I have had my stoma for forty six years so there is a lot to tell.

After I left school I was finding my stoma a real problem. Back in the early nineteen seventies bags were not particularly odour proof, so I contacted my stoma nurse at St Marks who suggested a new improved version of bag. I was then contacted by a doctor who was testing a foam enema

and I became part of his trial team. This gave me complete control of my bodily functions for the first time in my life. It was wonderful!

I felt confident enough to start driving lessons knowing that odour and noise would not be an issue. I also changed jobs, making a fresh start to my life, feeling normal for the first time in eighteen years. Unfortunately the enemas were withdrawn after about seven years due to the company not being able to obtain a patent. Fearing that I would be going back to the old life and worrying how this would affect my marriage, I went to my G.P. who referred me to the stoma nurse at the local hospital. She only worked part time and was very busy so she just handed me an irrigation kit and told me that I would find it too time consuming to use. I was desperate so, with no training, I had a go. It did take time but, as I became more confident with the equipment, I was able to spend less time in the bathroom. It never worked as well as the foam enema, but did give me some control and life was acceptable.

I ended up irrigating for twenty four years, including through two pregnancies, with only short breaks for various operations. It took determination and a little extra planning when the children were young but the benefits were well worth it. Indeed, I would still be irrigating now but, alas, I have hardly any colon left making it pointless to continue. I would certainly recommend irrigation to anybody who is frustrated by, or finds it difficult to manage their stoma, as it brings a degree of organisation to your life which, for some of us, would not normally be possible.

Luckily for me, the appliances are extremely good now and I have learnt to adapt to my new circumstances, not always happily, but when I think about it, it actually doesn't stop me doing the things that I want to do.

# Readers Writes...about Irrigation

## Dear Editor

I first heard about irrigation in the Colostomy Magazine, which was given to me shortly after my colostomy 18 months ago. I was trying to find out all about my condition and thought it was an interesting option. After permission from my surgeon, my stoma nurse provided me with a basic kit (irrigating bag, cone and sleeve) talked me through the procedure and I was off!

With a little organisation and patience both myself and my colon got into a routine. I irrigate on alternate mornings. It takes approximately forty-five minutes, which includes time for a shower and tidying up. I use a mini bag just in case my stoma begins to perform towards the end of the second day.

This has given me freedom and confidence. My kit goes on holiday with me. When I'm abroad I use bottled or boiled water and can adjust my irrigation time to fit in with flight time etc.

I would highly recommend irrigation to anyone for whom it is a possibility.  
S.P.

## Dear Tidings

I have had a colostomy, caused by a nasty cancer low down in the bowel, since 18th February 1984, two days after my 33rd birthday (Happy Birthday, Ha! Ha!). This episode occurred shortly after becoming a Warrant Officer with the Air Training Corps. I thought that would put an end to my training activities with the Cadets. Not so!

Within three months of leaving hospital, my stoma nurse persuaded me to try irrigation and I have never looked back. At first when 'it' was described to me I was horrified. You do what? Then that? Ugh! However, after much hard selling tactics by the good Sheila Jones, SCN, I capitulated and still irrigate twenty-one years later.

Because of Sheila's outstanding persuasive powers my activities with the ATC have been second to none. Along with others I have climbed, abseiled, walked miles and camped overnight (sometimes for a week), flown in gliders and two-seater planes, gone away on courses and annual camps, run rifle ranges and an assault course.

Oh! I nearly forgot; I held down a full time job somewhere in that time too, and achieved two life ambitions: gained a first aid trainer certificate and taught Royal Air Force recruits in Engineering at RAF Cosford.

Somewhere in amongst that lot, my wife and I have managed to bring up two kids. Our daughter was born two years after my surgery. We were so pleased.

Holidays – yes please. We have been abroad to hot and cold climates, done the Florida parks and malls more than once (Oh my feet!), visited Poland in the winter, (WHY?) and cruised (MORE PLEASE!). Next year we drive through Poland - this time in the summer.

### *My point*

1. A colostomy does not hold you back or prevent you from achieving the things that you really want. In fact, my colostomy probably spurred me on and made me that little bit more competitive.

2. Irrigation sounds Ugh! Don't knock it till you've tried it. Irrigation has made everything so much easier, giving ME control over my colostomy. Don't get me wrong, I have had all the mishaps you could think of and probably a few more but I wouldn't stop irrigating for anything.

A.D.

## Dear Editor

I was diagnosed with bowel cancer in 2005 and had chemotherapy and radiotherapy followed by surgery in November. When I was first diagnosed I

had been told about irrigation and was determined to try it. However the hospital staff were completely negative about it. They told me that it was a huge commitment; it was easier to use a bag and I probably wouldn't be able to do it anyway!

In April my local stoma care nurse taught me the procedure and I have been practising it daily ever since. It takes me about twenty minutes – not much longer than I would normally spend in the bathroom – and I can definitely say that it has changed my life. To me the prospect of a colostomy was worse than having cancer. I am 56 and enjoy sports, running and riding. I can do all these and feel so confident now when I am out and about. Most of the time, I forget that anything has happened to me at all.

My consultant tells me that in the USA 98% of people irrigate and that in the UK 98% do not. I think that this procedure should be promoted far more in hospitals. After all, at least give the patient the opportunity to have a go.

Yours faithfully  
S. H.

## Dear Editor

I had my colostomy at the end of August 1998 – and felt that life would never be the same again. Of course life is different, but one can overcome these things. However, I did find it hard to cope with the vagaries of my bowel. I have now irrigated for seven years, give or take a month or two, and I find it the best way to regulate/ease my life and to live the lifestyle I wish to have.

In 2000 we travelled to Australia, with my brother and his wife, to meet up with our other brother and sister and their families. As siblings we had not all been together since 1958. We had six weeks travelling in Australia without any hitches.

We have also driven through France and Spain and on to Portugal many times. In





2002 we toured Morocco, and, with hindsight, I was very lucky not to acquire an infection whilst there, as I used tap water throughout - of course we only drank bottled water!

I bought a battery operated irrigation machine at the end of 2002. This has a water tank which tells me when the water is too cold or hot, and pumps the water into the bowel. It makes for a much easier way of travelling as I do not have to frantically search for somewhere to hang the water reservoir. I do, however, carry the water bag with me everywhere - just in case I cannot recharge the batteries.

The only downside is that of air travel, when the machine needs to be in my hand luggage - not a simple thing at present. It seems to be examined in detail at every airport - 'what is this?' etc.

I had a hip replacement in 2005 which necessitated irrigating in hospital - a very uncomfortable experience - not one I wish to repeat.

I would not willingly go back to wearing a bag on a daily basis, besides irrigating must be a lot cheaper!

Yours sincerely  
J.S.

## Dear Editor

As I have only been irrigating for two years I am not yet a 'pro', but am still close enough, to the first scary time I tried it, to remember the horror. I must admit to finding it not only daunting but a mystifying, very un-charming process.

Un-charming, but well worth conquering. It is an exchange - setting aside one not very nice hour for two days of normality. Some people with a slower digestive system will find that they can 'last' for three days, but two days is more normal. My peristaltic movement in my 'whole' days was as slow as a snake digesting a rat; sometimes three weeks would elapse between movements.

I digress, however. After the operation and waking up to the clear plastic bag, then the skin-tone pink horrors and all the performance with changes, sore skin and disposal problems, to be now wearing what amounts to not much more than a sticking plaster over my stoma is sheer joy. To have two to three full days and nights of normality is worth that horrid hour spent in the bathroom. Each tiny minute spent irrigating gives you approximately one hour of total freedom from worry or even remembering you're not like other people, not 'whole'. The three inch diameter sticking plaster wins every time.

Irrigation is, sadly, not possible for everyone. But if you are able, you really need to give it a chance. I so nearly gave up after a month then I got into the rhythm of it. I now absolutely loathe the odd day or so when I have to revert to a bag if I'm off-colour.

As my wonderful stoma nurse, now sadly retired, said "Choose a quiet time of day and stick to it." So, as I have a shower in the morning, I chose before breakfast as my time for "my medical procedure" (for anyone who needs to know urgently where I am.)

What follows is obviously not a stage by stage guide about how to irrigate: you need a stoma nurse's assistance and your doctor or surgeon's permission. But it helps to have a checklist of things to have by you for the duration of the procedure.

A warm bathroom, a comfy wooden loo seat (it's warmer and more forgiving, so we changed ours from plastic), a radio within reach, and a warm, washable, fleecy top or dressing gown. Warm walking socks or fleece slippers are a good idea too, as one chills very quickly sitting still for that long.

Write out a list of your wants and needs, as once you start you can't really move for at least twenty minutes - I have the phone near my feet as well as the radio.

Check list as follows:

- 1.Scented candle, lit before you start, or room spray.
- 2:'Sleeve', belt and plastic supporting plate to be affixed around your middle.
- 3.Hanging bag of two litres of warm water, tubing and nozzle/tip.
- 4.Plastic jug, filled with one litre or so of warm water, for swooshing and cleaning the 'sleeve'
- 5.Three pegs: Two for plastic 'sleeve' and one for fixing clothes out of the way.
- 6.Clock or watch (to make sure you've spent your 20 minutes of boredom.) Never rush it.
- 7.Old flannel for mopping up water spills.
8. A Zen frame of mind, and you're off. And you'll never regret it.

H.C.



# Irrigation Works for Me...

Evan Robinson



Regular readers will remember Evan Robinson's previous articles in Tidings. He wrote about his challenges all over the world to raise money for Macmillan Cancer Support: running the New York Marathon, trekking across the Sahara, climbing Mount Kilimanjaro and following the Inca Trail in Peru. In this issue he describes how he uses irrigation to manage his stoma...

## First Feelings

When I opened my eyes the surgeon in his green smock was looking down at me. "Welcome back Mr Robinson. How do you feel?" "Like a steamroller has run over me" I answered. He smiled. I presumed it was normal to feel like that. "It went well" he said. "Temporary or permanent?" I asked. "Permanent, I'm afraid," the surgeon answered. "Damn!"

I watched the strip lights pass over my head as I was wheeled back to the ward. It was over. My bowel tumour had gone. I didn't have cancer any more. It was the 14th February 2003 - Valentine's Day. My name is Evan Robinson and at 56 years of age I had just had an operation to remove a Dukes 'A' bowel tumour. If one has to have bowel cancer a 'Dukes A' tumour, apparently, is the one to have. No radiotherapy or chemotherapy was required. However, because the tumour was very low down in my bowel, it was not possible to rejoin the colon. The resulting colostomy is therefore permanent. My digestive tract now ends in a stoma on the left side of my abdomen just above my belt line. I had chosen this position before the operation and Janet Sheridan, my colorectal nurse, had indicated it with a marker pen. Three days after my op I enjoyed a very welcome hot shower. Standing in front of the mirror I stared at the pouch stuck to my abdomen. I didn't want people looking at me thinking: "He's got a colostomy, you can see the pouch." People will know about my colostomy in my time and under my terms.

## Irrigation

During a stoma management session with Janet, I learned about the benefits of irrigation. Irrigation, Janet explained to me, is the process of feeding a quantity of body-temperature water through the stoma into the colon. The water triggers a peristalsis reaction that pushes the stools out of the stoma, thus emptying the bowel. There is a period of time before the bowel fills again and so the ostomate benefits by having no discharge from the stoma. The period is variable but could be as much as three days. I decided that irrigation, if it worked as Janet described, was for me.

My first attempt at irrigation was in hospital under Janet's supervision. She produced a drainage sleeve made from thin transparent plastic sheet. I stuck the top end to my stoma in the same way as a pouch. Sitting on the toilet the bottom end of the sleeve dangled in the water so I folded it back on itself like a cuff, so it was just clear of the surface.

Janet suspended a plastic bag containing one litre of warm water just above my head. A small tube from the bag ended in a cone so that it fitted any size of stoma. There was a valve in the tube to regulate the flow of water. I took the cone and, through the open top of the drain, pushed it gently inside my stoma. With my other hand I opened the valve to allow the water to flow under gravity pressure. I adjusted the cone until I felt my stoma accept the water and watched the level in the bag slowly fall, regulating the flow with the valve. When it had all gone I closed the top of the drain and held it with plastic clips similar to clothes pegs. After about a minute I felt my bowel react. Janet was pleased. My feelings were a mixture of embarrassment and relief. She told me to be patient; the peristalsis reaction could take up to 45 minutes. When the discharge had finished I removed the drain and had a shower. I felt clean and confident.

For the first few 'irrigations' at home I used the toilet. But I found that sitting on a toilet seat for 45 minutes or more was uncomfortable. I tried various ways of making myself more comfortable: cushions, towels etc. And there was also the problem of toilet occupancy time. There had to be another way. So I thought up a cunning plan!

## Privacy in My Privy

I have a study, my private space. It's only a box room, just big enough for a computer desk. From a local hardware shop I bought a small plastic bucket, two screw-in hooks and a bottle of perfumed toilet fluid. One hook I fitted to the wall by my desk just above head height when sitting. The second hook I fitted under the desk where my knees went. I made sure the hooks were strong enough to do the job intended. Spillage was not an





option but I spread some old newspaper on the floor as a precaution. I put a small quantity of water in the bucket, added a drop of toilet fluid and very carefully suspended it from the hook under the desk, making sure it would not fall off! With the valve in the plastic tube closed I put a litre of warm water in the irrigation bag and attached it to the hook on the wall. Sitting at my desk I stuck the top of the drainage sleeve to my stoma and put the bottom end in the bucket. Having checked everything was ready I carefully inserted the cone into my stoma and opened the valve on the plastic tube. When the bag was empty I closed the top of the drain, fitted the pegs and waited for the peristalsis reaction. It was comfortable, private and convenient and an appropriate opportunity to read my Tidings magazine!

After 45 minutes I carefully pegged the bottom end of the sleeve to the top to catch any late discharge. I was mobile. I poured the contents of the bucket down the toilet and washed everything. A wave of deodorant spray finished the job. After a shower I dried myself and attached a stoma cap. That was three years ago and my method at home has not changed. The time I stay clean varies but the average is between 36 and 48 hours. Wearing a stoma cap after 36 hours is risky.

## Challenges

In May 2003 I accepted an invitation from Macmillan Cancer Relief to run the New York Marathon. I wanted to irrigate before the event but would there be anywhere to hang the irrigation bag? There had to be another way to irrigate my stoma. Tidings described a battery operated water pump that could operate from the floor if necessary. My Primary Care Trust bought me one and I took it with me to New York. I irrigated the night before the Marathon and wore a stoma cap during the race. I felt confident in front of the New York crowds even with a sweaty tee shirt that stuck to my skin!

Since then I have taken part in other events for Macmillan including trekking across the Sahara Desert, climbing Mount Kilimanjaro, and the Andes Mountains in Peru.

The Macmillan Sahara trek presented new challenges for me. Conditions would be



basic: toilets just a hole in the sand. And no litter could be left behind. So what about my used pouches? I couldn't carry them with me! The answer was flushable pouches which are also biodegradable. The pump also worked well in the Sahara. Sitting on a sand dune in the evening I irrigated my colostomy under the desert stars. It is a memory that has stayed with me!

On the Peru challenge I made a serious mistake. We had made camp in the Andes Mountains and I wanted to irrigate. A Peruvian guide gave me some warm water and I used it to irrigate. During breakfast the following morning I felt ill. The guides put it down to the altitude sickness. We broke camp and continued our climb into the mountains. By mid morning I was vomiting and a porter was ordered to get me off the mountain. But even at lower altitudes I was still nauseous. Then my stoma started to work and the pouch filled. I changed and after a few minutes that pouch filled too. I had that most dreaded of ostomate afflictions: diarrhoea. I was using pouches at an alarming rate. I took some diarrhoea tablets and the discharge slowed.

It wasn't altitude sickness. The water that I had used to irrigate had not been drinking quality and my bowel had absorbed it. It was an important lesson learned the hard way.

## Bag or Pump?

As versatile as the pump is, I still prefer the suspended bag. I think it is because the bag works by pressure and the pump by flow. The pump cannot vary water pressure, only flow. What does this

mean? It means that for all its convenience, the pump is not as good for irrigation as the suspended bag. The manufacturer that invents an irrigation pump that controls pressure rather than flow has got my vote.

On the Kilimanjaro Challenge I tried a different way. I bought a cheap camera tripod with a handle at the top on which to hang the water bag. With the tripod legs extended and sitting on the ground the bag was just above my head height. As a hook was not needed I could irrigate anywhere. I practiced at home until I found a technique that suited me. My 'kit' went with me to Mount Kilimanjaro and it worked!

Irrigation was easy even at over 15000 feet. But more importantly I didn't have to worry about rucksack straps rubbing on a pouch.

## Lifestyle

Caring for my colostomy is personal and private. But my activities often mean living in close proximity to other people who don't know me. Sometimes there is no choice and my stoma and what I have to do to care for it cannot be kept secret. Two fellow trekkers walked by when I was irrigating in the Sahara Desert. They gave me a curious look until recognition came over their faces. I was glad I had earlier told the whole group about my colostomy. Irrigation means that my colostomy doesn't get in the way of my lifestyle. Irrigation works for me and I can do it anywhere.



# Irrigation using the Braun Irrimatic Pump...

Judith Franks



If you already irrigate your stoma, you might consider using The Pump. I've used it since it first arrived in this country from Germany. Seven to eight years ago Braun asked me to 'trial' it and write a report. It now comes with a brief User Guide, so this account is simply my personal observations as a user, outlining what I see as its chief advantages and drawback.

The Pump, which comes with all necessary accessories, a carrying bag and a two-year warranty, is a square jug, measuring about 18cm in width, depth and height, battery-operated, charged from the Mains. It needs charging for 24 hours before using it for the first time and, according to the User Guide, should remain connected to the electrical supply until used again. I learnt first-hand, however, on my first visit to the States, that constant connection between one use and the next is not essential. I'd gone equipped with a Universal Adaptor but quickly realised that 'Universal' doesn't include the USA! Their voltage system is quite different from any others – even South America, where I had no problems charging at all a few years later. Anyway, I panicked, as I hadn't learnt by then that you always travel with a 'back-up system' and saw myself having to survive a week without being able to irrigate. In fact, I needn't have worried as the Pump survived quite happily all week, without needing to be recharged at all!

Now, I charge it once a week and it's only ever 'run out' once – on the last night of a stay in Peru, about which you might have read my Article in Tidings a few years

back. But, at least by then, I'd learnt to carry a 'hang up' bag for use in an emergency!

Anyway, back to everyday use. Unlike other more fortunate colostomates, I need to irrigate every day – after all, before I had a stoma, I 'went' every day, so why should my body-rhythm have changed? It only takes 15-20 minutes in any case, much less time than a very good friend of mine, without a stoma, passes in the bathroom every morning!

I pour a litre of warm water in the jug – I've varied the amount between 250ml. and 1 litre over the years, but the quantity of water depends enormously on how often you irrigate and the size of your colon and has nothing to do with whether you use the Pump or the traditional 'hang-up' bag. As for the heat of the water, there are red and green buttons on the front of the Pump for water-temperature display, so you can't get it wrong.

I place the pump at my feet, or on a table beside me, depending on where I am, and sit on the loo with the cone, (connected by tubing to the pump) inserted in my stoma, through the irrigation sleeve which dangles through my legs into the loo – in the same way as with other irrigation kits. The pressure-adjustment switch on the top of the Pump ensures a smooth flow of water and the litre goes in, in less than 5 minutes. Once again, speed depends greatly on the individual and the height at which the Pump is standing, and I know most irrigators, whatever their method, take longer than me. But a highly-respected French Stoma Care Nurse once told me that it's a question of logic and the basic laws of gravity – the faster the water 'goes up', the further it will get before it starts to 'come down' again, so the cleaner will be the 'flush out'. Anyway, remember this is a personal account and don't hesitate to be advised by your Stoma Care Nurse if she says differently!

After about 10 minutes and four to five 'emissions' on the loo, I rinse out the irrigation sleeve, roll it up, secure it carefully with the clips provided or freezer-bag clips. I wash out the Pump

Jug and go off to spend 10 minutes on the Exercise Bike, check my e-mails, eat my breakfast etc, just like any other Irrigator during the 30-minute or so 'draining' period. Then, about 50 minutes after getting up, I remove the irrigation sleeve and have a shower, before putting on a small bag and getting dressed.

This all sounds too good to be true I hear you all saying – so where's the catch? And yes, there's a big one – the Pump is not on the NHS and costs £325! You can imagine I've taken the matter up with Braun but they say there's not enough demand for it to justify the Government subsidy, but anyone can see it's a 'chicken and egg' situation – if something costs so much, there will be less demand, so there's less justification for the subsidy, so it costs ... I personally feel the Pump is worth the money as I was not good at regulating the flow on 'hang-up' devices. I also travel a lot and lack the imagination to be innovative in other peoples' bathrooms. My pump has never yet 'gone wrong' in seven to eight years (touch wood!) and the rechargeable batteries don't need changing nearly as often as the every two years or so the Guide suggests – at least, mine don't!

If, in spite of the cost, you'd like to give the Pump a try, contact Braun (0800 163007). They will allow you 'a trial run' before you buy, but they will only deal with you through your Stoma Care Nurse. She needs to know you're using the Pump and approve your use. If you wish to talk more about my use of it, and the experiences of several other colostomates I know, feel free to ring me on 01953 452484.



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Ernie Hulme

Back in the spring of 1994 the imminent arrival of the warm weather was being heralded by the blossom appearing on the trees and the steady stretching out of the daylight hours as preparations were afoot for the summer. As someone that loves the long hot summer days I would normally be looking forward to this time of year and would start the celebration of summer by digging my shorts out of hibernation much to the displeasure of my neighbours, one of whom believed my legs had been purchased from a local car boot. This year, though, was going to be different than all the others and it would see my world being up-ended and changed beyond all my expectations.

## Plug or Pouch

After a series of tests and minor procedures that saw complete strangers studying parts of my anatomy that only my wife and mother had the rights to see, I found myself sitting alongside Carol, my wife, in a small consultation room faced by two immaculately dressed consultants. My chin was somewhere on my chest and I was squeezing the dear life out of Carol's hand wondering why I could see the doctors mouths moving without any sound being made; it was very much like a silent film show in slow motion.

I had just gone deaf after hearing two words: Cancer and Colostomy.

As those that have experienced any form of cancer will know, it's the start of a very surreal time not only for the person diagnosed but for the whole circle of family and close friends. We as patients have the disease and our loved ones suffer alongside us, much of the time in complete silence. Virtually everything changes. Our values, outlook, priorities and emotions all come under scrutiny and we look deep into things - not just at them.

My "bottom transplant" surgery would be following a course of chemo and radio therapy and according to the surgeon if the alien growing in my rear end responded well to treatment and shrank in size he would go in and remove it early in the New Year. It all sounded very straight forward.

After the psychological dust had settled, I began to make a mental list of priorities. I thought myself a very clever chap for doing this but, since becoming involved in patient support, I realise almost everyone has a list of goals and objectives. The list changed quite often as my treatment progressed and it contained some very strange wishes.

As Christmas came and went and my surgery got closer I found myself checking light fittings, fuses and general "Man" things as I thought Carol would appreciate this if I didn't make it back home.

Sitting in the number one and two spots were: one "Waking up" and two "Being rid of the Cancer". The thought of a pouch being permanently attached to my abdomen was, at this time, not too big an issue - but all this was about to change. The day after my surgery I woke up on the high dependency ward. That was number one sorted. A week later I was confidently told by the surgeon, still immaculately dressed, that tests would more than likely confirm that the cancer, along with my tail end, was gone. That was number two off the list as well.

Over the following weeks I worked my way down the list, confidently addressing each item in turn. I had returned to my local swimming pool, started back to work and sampled a cold glass or two of Guinness without any problems, but working its way slowly, but surely, to the top of the list was the issue of body image and sexuality.

Like our breast cancer sisters that have had a mastectomy we also have a constant physical reminder of our brief encounter with cancer.

My first attempt to "hide" my stoma was with a light support belt. I had obtained the lightly elasticised garment initially as a preventative measure after reading about hernias and, as my work sometimes involved heavy lifting, I thought better safe than sorry. I would tuck the bottom of the pouch under the garment and, apart from looking like an over exposed sumo wrestler, I appeared almost as I was prior to surgery.



For anyone wishing to hide an ostomy pouch, this belt, that resembles a panty girdle, could be the ideal solution.

Then quite out of the blue at my first patient open day I heard about Plugs. At first I had all sorts of visions in my head. Would I have a screw like mechanism attached to my tummy into which I screwed this plug? Was it like an electrical plug and socket, or the plug in my bath?



After contacting my Stoma care nurse she invited me along to the hospital where I was introduced to my first plug. The Conseal plug, patented and manufactured by Coloplast, was the brainchild of a Danish consultant working in collaboration with the company. It was first introduced way back in 1988 as a two piece system. The aim then, as now, was to give people with a Colostomy a significantly higher degree of discretion, comfort and security. Used in conjunction with irrigation the benefits are many fold.

As the business end of the plug is inserted into the stoma, the visual appearance is that of a flesh coloured, round plaster stuck to your tummy. Any wind is filtered down the stalk and through a good charcoal-based filter outlet and, to this day, I have never had any problems with odour. Being the sort of person that falls on the floor with laughter when hearing a trumpet or "bottom cough" (Can anyone remember the late great Peter Sellers in the Pink Panther lift scene?) it may seem

strange for me to say, but breaking wind without control was one of my worries. The plug takes away this problem completely, because it is inserted into the stoma thus removing the chance of a noise. Need an example, try blowing a raspberry with a finger in your mouth!

As the theme in this edition of Tidings is Irrigation I thought you would like to read about the benefits of the Plug when used by someone that is irrigating or considering irrigation. However, there are a great many people with colostomies that either don't or can't irrigate and I am one of these people. As I have a minor heart condition introducing fluid into my large bowel, from where it may in turn be absorbed into my system, is not recommended - hence the need to consult with your Stoma care nurse or Nurse Specialist before starting irrigation.

My main method of stoma management is my trusty pouch but I use the Plug "selectively" and, to be perfectly truthful, I would be lost without it.

The plug is not something I would personally recommend too soon after surgery and not something that can immediately be accepted as the bowels first reaction is to push it out along with the motion. However, the benefits are more than worth it when these minor and very short lived teething troubles are overcome. If you are fortunate to have a relatively regular bowel habit and know 90% of the time when you are going to need the toilet, life with a plug can be great. With a wear time anything from half an hour to twelve hours, swimming, sporting activities, communal showers and sunbathing are no problem... and I might add - hopefully without embarrassing my children who believe their dad to be a monk and their mum to be Maria from the Sound of Music - those special times with your partner become very special, uninhibited and, in a way, normal - Sorry kids.

Irrespective of age, sex or lifestyle our body image is very important to us. At the end of the day, other people's opinions on how we look are welcomed and in some cases needed, but it's how we look and feel about ourselves that is important. After a period of rehabilitation and adjustment, almost all of us return to a near normal lifestyle and this positive addition to my stoma management kit gives me the ability to look the part as well.

Product information and literature is available from Coloplast on 0800 220 622 but remember to consult your Stoma Care Nurse, Nurse Specialist or appropriate medical professional for assessment prior to using this clever and discrete form of management.

**Ernie Hulme**





# Dear Nurse...



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

**Q:** I have had a colostomy for over twenty years due to bowel cancer at the age of thirty-five. At the time I was fortunate to have a stoma care nurse who encouraged me to irrigate, which I have done ever since, with no problems until a few years ago. Then I started experiencing difficulty introducing the water into the stoma. It seems very strange to me that some days the water cannot find its way in.

I did speak to my current stoma care nurse, but unfortunately I don't think irrigation was her speciality and she advised me to stop. This I was not prepared to do, as without irrigating my stoma would work whenever I ate.

I have had a colonoscopy just to check that everything was OK and was reassured that the results showed no medical problem.

Lying down while the water goes in often helps - but not always. It is strange that once I have succeeded in getting the water in and my system flushes out, it is then easy, while sitting on the toilet, to introduce a further small amount of water to ensure everything has been cleared out.

For most of my adult life I have weighed eight and a half stone, but my weight has

now increased to nine stone three pounds. Do you think this could have anything to do with the problem? I am hoping you might be able to suggest something I haven't tried.

**A:** It may be that you are having difficulty inserting the water into the stoma due to increase in weight, although the weight gain you describe is not excessive. Or it is possibly due to a parastomal hernia. This may explain why on some occasions it works whilst on others it is a problem. Changing the position you sit or lie in when inserting the water can help, as you have found out. As long as you are willing to adapt the way in which you carry out the procedure you should be alright to continue as you have been checked by the medical team to ensure there are no medical reasons behind the problem.

**Q:** Further to the letter in the last issue from a gentleman whose father suffered from rectal pain, I am writing to say that I have a similar problem.

In April 2004 I had my anus and rectum removed. Since then I have experienced rectal pain. Mine is best described as like having my buttocks sewn together so that when I sit down it becomes uncomfortable.

My consultant diagnosed trapped nerves in the scar tissue of my anus, but, despite a course of steroid injections followed by a course of acupuncture, I am no better.

Is this a common occurrence and is there anyone out there who can help me get to the bottom of the problem? (pardon the pun!)

**A:** This is quite a common problem following this sort of surgery. There are many different ways to try to solve the problem, steroid injections and acupuncture being two of them. It may be beneficial to ask your Consultant Surgeon if he can refer you to a Chronic Pain Specialist Consultant who will be able to discuss other options with you to attempt to solve or at least ease the discomfort.

**Q:** I am a nurse but am enquiring on behalf of my sister-in-law who has a colostomy. She tells me she still gets an overwhelming urge to open her bowels via her rectum, but nothing ever comes out. She says she comes over all 'goose-pimply' and is desperate to find a loo. Is this normal and is there anything she can do about it?

**A:** You do not say if your sister-in-law had her rectum removed or if it is still in place. If she did have it removed these are possibly 'phantom' pains and are quite normal, if irritating. It could also be due to a perineal hernia which would require surgical review to see if it could be repaired surgically. If she still has her rectum in place the feelings could be due to a mucous plug and a digital rectal examination could help to diagnose this. Once the medics are happy this is the cause of the problem rectal glycerine suppositories can be given to help to remove the mucus.

**Q:** I have had my colostomy for many years and have been plagued by prolapses of the stoma. Last year I had it re-fashioned, but already it has started to protrude again. I wonder whether you could advise me if it would be better to have the stoma re-sited. My concern is that I would be given an ileostomy, because I have only a small amount of colon left. I would then be concerned about the ileostomy prolapsing as well. I am not particularly over weight and am a very active fifty-one year old.

I have spoken to a number of stoma nurses and have had varying advice. I would appreciate your opinion. Lastly, is there anything that I could do to prevent my stoma from prolapsing? I do already wear support garments.

**A:** Unfortunately I cannot say if re-siting your stoma, with the potential for an ileostomy would be appropriate, this is a decision you need to make after a detailed consultation with your surgeon. Re-siting would certainly be a possibility if your Consultant was in agreement, although there would be no guarantees and this stoma could prolapse again. You are already wearing support garments so I would suggest you ask for a review with your Stoma Care Nurse or your Consultant to discuss the problem in more depth.



## Dear Nurse...







# Experiencing "Phantom Pain"...

I was interested to read of the man with phantom pain as I have experienced the same ever since stoma surgery eleven and a half years ago. So much infected tissue was removed along with my rectum that the space had to be "filled" with a muscle from my thigh, which was rotated and packed into this cavity. The infection was caused when waste material got under my skin as the tissue had broken down so badly in my rectum; this then caused a six inch diameter abscess on my buttock. My weight dropped from thirteen stone to just seven stone and the poison infection created septicaemia.

After time in intensive care, three major operations, plastic surgery to my groin and the abscess site, I literally staggered out of hospital after four months in bed.

Walking, with my border collie, Sam, enabled me to become stronger, although it did feel as though I was walking with a ball implanted in my tail. Attending pain clinics and using Tens machines did not help. The phrase "phantom pain" was used which is, I feel, an unfortunate term, as the pain is very real when sitting as well as standing and walking. I do feel that the muscle isn't happy there, nor is the tissue around it.

I was given a made-to-measure soft foam cushion, which follows the contours of my seat. I still use this and take it on holiday and to the theatre. Over the years the pain has lessened, although I still take a reduced dose of Paracetamol and Tylex if it gets worse due to me being more active. After eleven years or so I find it easier to live with and am more accepting of the pain and my transverse colostomy. I use drainable pouches, as I get quite a few movements in a day. A large portion of my colon was removed, resulting in more fluid waste, as less water is absorbed.

When I spoke on the phone today to Beryl Goddard at the Colostomy Association, she suggested that I should ask my G.P. if an injection may be possible to ease my phantom pain, which I will try. We also spoke about emotional and psychological issues after stoma surgery. When I first visited my G.P. after leaving the hospital we discussed my feelings of loss and changed body image: a sportsman with a six-pack, which has now become a bulge as the muscles were severed to get to my colon. As well as the challenges in intensive care I also felt some emotional relief that I was being cared for and I was



Phantom Pain - "Attending pain clinics and using Tens machines did not help. The phrase "phantom pain" was used which is, I feel, an unfortunate term, as the pain is very real when sitting as well as standing and walking."

"When I spoke to Beryl Goddard at the Colostomy Association, she suggested that I should ask my G.P. if an injection may be possible to ease my "phantom pain", which I will try. We also spoke about emotional and psychological issues after stoma surgery."

getting practical attention for a health problem that had blighted me for over thirty years.

Back at home I did feel that I was reborn which had its elements of glad-to-be-alive. However, I also felt very vulnerable, with all my coping mechanisms broken down. I found that I related to Terry Waite's isolation in being held hostage - whereas I was held in hospital finding ways to survive and making friends with nurses rather than captors. In recent years there has been a rail crash quite near me in Hampshire. I feel that my emotions are the same as those experiencing grief and loss: relatives and survivors who may have lasting physical injuries - all involved in

any way have lasting issues. Again I see this aspect reported on in ex-servicemen who suffered trauma, sometimes many years ago, and who still get tearful and suffer nightmares. Fortunately my nightmares are getting less.

I concluded my phone conversation with Beryl by agreeing that the British stiff upper lip is not always the best way to handle life's challenges. It is OK and healthy to feel and show emotions; it also helps to talk about our experiences and you can do this by contacting the Colostomy Association, where you can talk with people who know and care.

Self help groups also exist which, again, help you not to feel so alone. Despite my ulcerative colitis, which finally completely broke down when I had the flu, I had been a coach and athlete for the ten years directly prior to the hospitalisation. I do feel that this fitness together with the competitive instinct was a big factor in my recovery. I took every aspect as a challenging event. After at least ten doses of general anaesthetic along with many other pills and potions I found that exercise cleansed my system of any remaining toxins, and eventually I felt I could breathe more freely. I still maintain my exercise routine on my home multigym and sit up machine. This has enabled me for the last eight years to ride to Switzerland on my big motorcycle which has soft foam inserted into the seat.

Andy Morris



# Winter Warmers...

## Carrot & Coriander Soup

### Ingredients:

1 medium onion finely chopped  
1lb carrots peeled and sliced  
1 clove garlic, crushed  
1oz butter or margarine  
1 bay leaf  
1 tbsp. chopped fresh coriander  
Half pint chicken stock  
Half pint milk  
2 tsp. sugar  
Salt and pepper  
Fresh coriander to garnish

### Method:

Melt the butter in saucepan.  
Add the garlic, carrot and onion and cook until softened.  
Add the bayleaf, coriander and stock.  
Bring to boil and simmer until carrot is tender.  
Process or blend until smooth.  
Return to the pan, add milk, sugar and seasoning and reheat.

*Serves 6*

## Beef in Beer

### Ingredients:

2lb lean braising steak (cut into chunks and dipped in seasoned flour)  
2 sliced onions  
3 sliced carrots  
Half pint beef stock  
Half pint stout or pale ale  
1 tbsp. brown sugar  
2 tsp. vinegar

### Method:

Pre-heat the oven to 150 degrees C or Gas Mark 3  
Dissolve the brown sugar in vinegar in a heavy bottomed pan.  
Add the onion and steak, cook until brown.  
Add carrots, ale and stock.  
Bring to boil then transfer to the oven and cook for at least 3? hours.

*Serves 6*

### Colostomates' comment...

If you prefer to avoid onions, why not use whole un-sliced onions, which can be removed once cooking is complete. This will provide all the flavour without worrying about an embarrassing attack of wind!





## “Why are you wearing that funny hat Grandma?”

### Why Indeed?

If anyone had told me sixteen years ago that I'd be collecting a Masters Degree this year, I wouldn't have believed them. In 1990, following years of bowel problems, I had a colostomy. My job was gone, the future looked bleak. A small percentage of people who have stomas are left with continual rectal pain, which makes sitting down for long periods very uncomfortable – unfortunately I was one of them. What employer would want me if I couldn't sit down and concentrate at the same time?

I did get a job working from home, where I could stop, get up and walk round whenever I wanted. In 1999, I decided to retire and look after my grandchildren instead. I was also a volunteer for The British Colostomy Association and in my spare time I indulged my hobby of writing articles and short stories. Most of the manuscripts I sent away to magazines came back with the dreaded rejection slips, but I did get a short story and about a dozen articles published.

It was the tutor at my evening class in creative writing who suggested I apply for a place on an MA course in Writing at Nottingham Trent University. I dismissed the idea as well out of my league and anyway it involved two year's study and there were fees to pay. My husband said that wasn't a problem: Brierley Acoustics, his one man business, would sponsor me – after all I had proof read hundreds of noise reports over the last ten years – this would be a belated payment!

But I still had to be accepted. I sent off the application form and three samples of my writing and waited. To my amazement a letter of acceptance arrived, conditional on my providing a second reference. Catherine Plant, who some of you will remember as the Stoma Care Nurse at BCA, kindly wrote me that reference, and mentioned that I had done some work for BCA: ghost writing articles for



Nursing magazines and the Practitioner – medical experts had provided the facts, I just expressed them in words!

I was a student again! The reaction from our children was varied. My daughter, the youngest, laughed, my middle son was struck dumb and thought he'd misheard, my eldest son said, 'Great! Mum. Go for it!' It was quite daunting at first being there among people in their early twenties, who had just completed their first degree. But I wasn't alone: there were a few others of mature years, although, perhaps, not as mature as me!

We were expected to do most of the work on our own in the library or at home, which suited me fine, but there was one evening lecture a week to attend. Could I sit through one and a half hours without fidgeting? I managed. We also had to choose two options; I chose fiction and creative non-fiction. For these we had to attend fortnightly seminars and produce 3,000 words for the rest of the group to critique. A daunting

prospect. Nowadays I don't often think about my colostomy, but what if my stoma made a loud unexpected noise, while one of the other students was speaking? I decided that if it did, I'd just ignore it – I wanted the others to critique my writing not contemplate my plumbing!

Over the two years there were six assignments to complete, one presentation to give and a dissertation of 20,000 words to produce. There were times when I didn't think I'd manage it. But I did. I was awarded my certificate last November, the same month that I collected my pension and senior citizen's bus pass!

Rosemary Brierley

## Hints and Tips...from our Readers



When you are packing to go away on holiday, it is rather dodgy, I think, to pack your medical supplies throughout your luggage. To be stuck wandering around Florence with a bulging pouch, and your luggage en route to Bangkok, is not my idea of fun! Get yourself an A4 zip plastic wallet from any good stationers (cost about £1.50). This is about the size of a small back pack and will fit properly into the overhead lockers, which is all that is allowed in the cabin these days. The pouches, together with wipes etc., will lie flat inside the wallet, leaving plenty of room for all the other things needed for the flight. Doing it this way means that your medical supplies never leave you and the new airport security can be easily dealt with.

And Ladies, it is far better to have all your medical equipment with you rather than that Prada handbag of which you are so proud. Pack that in the main luggage instead!

A.H.

P.S. My stoma has a name. She is called Gucci! No, not after the handbag company, but short for Tamagochi. She makes peculiar noises at awkward moments and needs looking after on a regular basis!



A reader in Yorkshire sent us a newspaper cutting about the Clippasafe Bump Belt, which can be fitted onto a car seat belt. Designed for pregnant women, it keeps the lap belt low over the hips and pelvis which are better able to absorb any impact. She told us how her husband had bought one, as it

stops the seat belt riding up and pressing on his stoma. It is a small cushion with Velcro straps which is easily fitted and can make car travel more comfortable and safer. It costs around £20 and is available from some branches of Boots or on line at [www.clippasafe.co.uk](http://www.clippasafe.co.uk)



When changing a drainable appliance I was taught to rinse out the soiled bag by holding it under the flushing loo. However, as my output is thin and watery to thickish sludge - no formed stools - the cold water doesn't clean it very well and it took ages. I now fill a jug with comfortably hot water then I either sit well back on the toilet seat or kneel down on the floor. First I take the clip off my drainable bag, then stroke the contents back away from the open end to give an inch or so to fold back on itself to make the pouch end firmer to hold open. Then, before taking the bag off, I firmly hold the open-end and pour some water into the bag. Supporting the pouch in the palm of my right hand and keeping the open end closed between the fingers of my left hand, I gently shake the bag up and down, giving 'willows' (so called because of the excessive amount of wind in it in the early days - and now!) a lovely hot 'power shower'. I drain the bag, flush the loo, then repeat once or twice if not completely clear. I find this is a speedy way to clean the stoma bag

and wash 'willow' at the same time. Incidentally, if I can't get the pouch to stick I refill the jug and hold it against the pouch to warm the flange and get good adhesion. I have a fairly large hernia and fitting a flat surface to a rounded area is a problem. When the central heating is on I place the pouch on a towel on the radiator whilst changing and this helps to soften the flange so it moulds to my shape.

B.T.



If you need to go to casualty or are being admitted to hospital for some reason not connected with your stoma, remember to take a supply of appliances. There may not be Stoma Nurse around and, even if there is, she may not have your type of pouch in stock. When you arrive on the ward, if possible, ask Sister if there is someone who can change your bag. If not, ask if you can show a nurse how to do it.

R.M.

*If you have any hints and tips you would like to share with other readers, please e-mail or telephone Head office or write and tell us about them....*



## Name your Stoma Competition...

- ❄ Tell us what you call your stoma and you could WIN £25.00 of M&S vouchers.
- ❄ We are holding a competition to find the most amusing name for a stoma!
- ❄ Send your entries (including your name and address) to:  
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# Tidings

Dedicated to Colostomates and their Carers

Following the publication of our questionnaire in the last issue of Tidings, we received 216 responses and a summary of some of the key findings follow...

## Feedback Questionnaire Results

### Question 1

Overall, how do you rate the Tidings magazine?

**Feedback:** 89% of the responders rated the magazine as Very Good, with a further 10% rating it as good. This is an excellent result and shows that we are getting things right for the majority of our readers.

### Question 2

How frequently do you refer to your Tidings magazine?

**Feedback:** Just over a third of the responders referred to the magazine once a quarter, another third referred to it once a month and the remainder either weekly or daily.

### Question 3

Which articles in Tidings do you read?

**Feedback:** The most read articles in Tidings came out as Dear Nurse, Hints & Tips, Readers Writes, Reader to Reader, Articles by Health Professionals, Colostomates Experiences and the Editorial.

Articles with the lowest scores were Poets Corner, Putting the fun into Fundraising, Support Groups and Plants in Medicine.

### Question 4

Which articles in Tidings do you find the most interesting?

**Feedback:** Hints & Tips, Dear Nurse, Articles by Health Professionals, Readers Writes and Colostomates Experiences were deemed to be the most interesting.

Poets Corner, Putting the fun into Fundraising, Support Groups and Young Colostomates were seen as the least interesting.

### Question 5

Do you share your Tidings magazine with anybody? If so, how many people?

**Feedback:** A high proportion of responders did share their magazine but, usually, only with 1 or 2 other people.

### Question 5

What other types of articles would you like to see in Tidings?

**Feedback:** We had a lot of responses to this question and the most popular themes were Recipes, Nutritional Advice, Diet, Body Image, Pen Pals, New Products, Clothing and Psychological effects of stoma surgery.

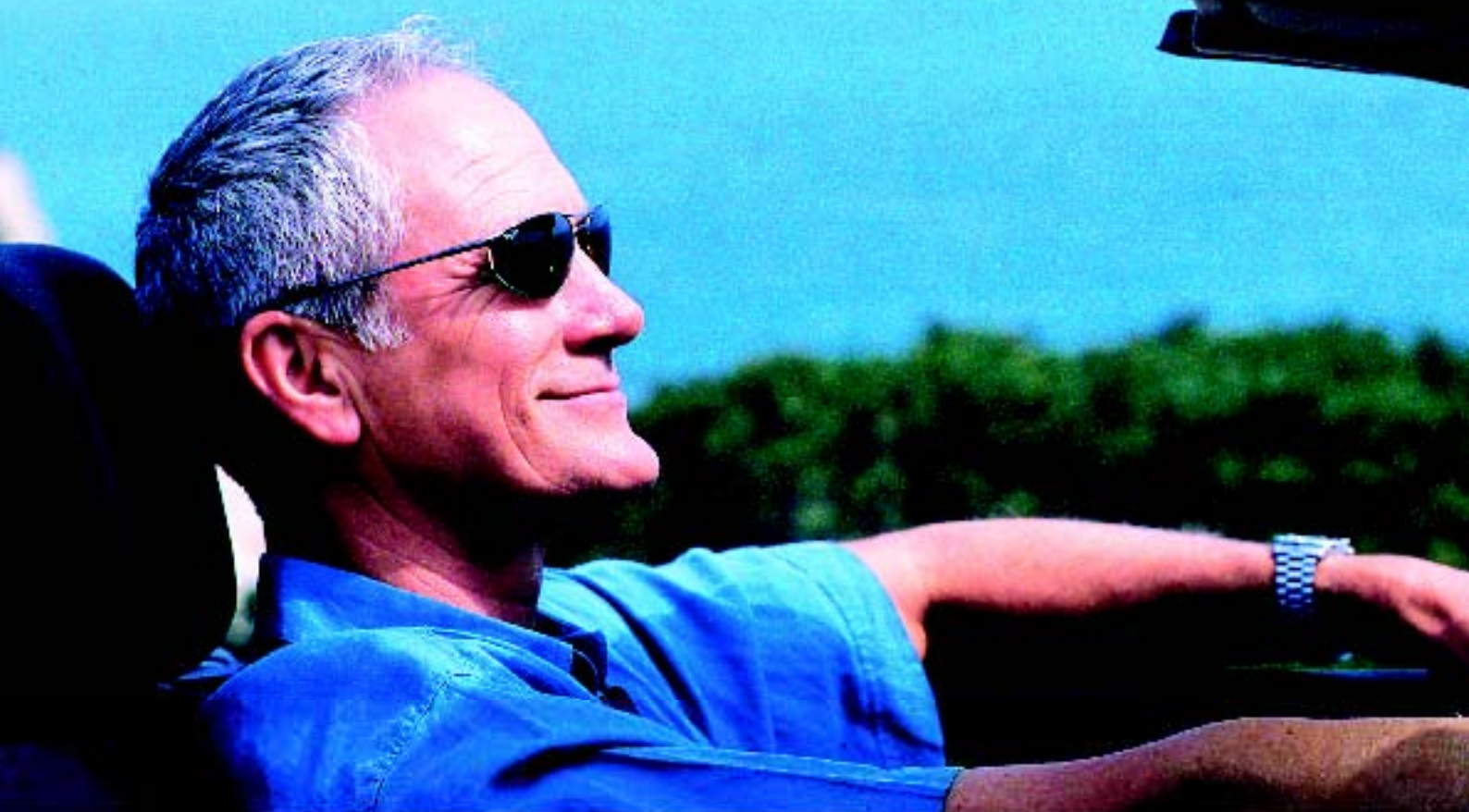
The editorial team were very pleased with the results of the survey and it has certainly given us a clearer picture of what you, our readers, want to see in the magazine. We will be reviewing the results in greater depth prior to the next issue and hope to incorporate some of your suggestions.

Thanks, once again, to all of our members who responded to the questionnaire.



# "Given the freedom of choice you can choose freedom"

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1. Periodically published study: OVI & P.O. Research at VIOET Conference, Bristol 2004

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## Support Group in the Spotlight

### Guernsey Ostomates



Members of the group enjoying a cup of tea and a piece of cake inside Bulstrode House



Toucan Open Day. From left to right Sue Bache, Andrea Musson (Stoma care Nurse), Simon De La Mare

*Dave Allen explains why and how, in November 2005, he set up a support group for people with colostomies, ileostomies and urostomies in the Channel Islands. Less than a year later the group's contact list has grown to 139 ostomates, friends and relatives who live in Guernsey, Herm, Sark and Alderney.*

When I was a teenager many years ago I lost my best friend due to cancer of the bowel. At that time, I knew nothing about a colostomy: how it worked, what it did or what it looked like. Little did I know that some fifty years on I would be diagnosed with the same condition, but would be one of the lucky ones who would receive the life saving operation, which to me is a bonus. My surgery was four years ago and it took twelve months to recover because I developed MRSA. After discharge from hospital it was found I had a secondary cancer for which I have been receiving chemotherapy.

There is a saying: 'You don't know how many green cars there are until you buy one yourself!' Until I had my colostomy, I had no idea how many people in the world also had a stoma. Yes, I can be angry and say why me, or blame others for what has happened. But, having lived with my colostomy and managed to adapt to a way of life that suits me, I do not consider that I am any a less of a person than before my operation. So with this in mind, I set about establishing the Guernsey Ostomates.

The stoma care nurse, we had at the time, did not want to become involved. However, I found a friend in the lead cancer nurse who provided help and advice. I contacted the local radio station and they gave me a forty-five minute slot to talk about colostomies and what it's like to have one. The programme went down well and a month later the B.B.C. gave me more air-time to talk about the group I wanted to set up. This coincided with the appointment of a new stoma care nurse, who was in favour of patient support. B.B.C. Guernsey then put me in contact with the Jersey B.B.C. and so I went down to Jersey and did another forty-five minute show on their radio. This also gave me the opportunity to meet the Jersey Ostomates and get some ideas for my group.

I started my group in November 2005 and I had five people turn up; by March 2006 we had forty people on the books; by July 2006 we had 120, although some of them are carers. Over the last 12 months our contact list has grown to 139.

Our meetings are held every month at Bulstrode House, the treatment room for people receiving chemotherapy at the Princess Elizabeth Hospital, Guernsey. It is called Bulstrode House because it is fitted out like a house: a sitting room with easy chairs, a television and radio, plus a kitchen. There are always fresh cut flower on display in reception and always a person from Guernsey Cancer Relief on duty. The whole area is calm and relaxed.

We are a self help group; our meetings are informal, we supply tea and coffee, pass on tips and hints plus contacts to other groups or charities that can be of help. We also have guest speakers and

arrange events. At this moment in time we are planning the Christmas dinner. I still go on Radio Guernsey every now and again to keep everyone updated about what the group are doing.

Although the total population of The Bailiwick of Guernsey is quite small (80,000), the area we cover is large. From Guernsey it is three miles across the water to Herm, eight to Sark and about twenty to Alderney. This means that not all our members can attend our meetings. Therefore, we run a postal service to keep in touch, and every member receives a copy of the minutes of the last meeting. I find that, because quite a few of my members are getting on a little, they enjoy the contact of the written letter.

We have our own email address [GuernseyOstomates@cwgsy.net](mailto:GuernseyOstomates@cwgsy.net) and we are building a web site. Our telephone contact number is 01481 701099

Dave Allen

*If you would like to be included in 'Support Group in the Spotlight' do write and let us know about your group; have you recently celebrated a special occasion or had a visit from an interesting speaker? Would you like to tell readers about an event you have arranged for the future? Ed.*



# Pelican Healthcare Introduces . . .

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All Convex pouches should only be used after prior assessment by a stoma care specialist.



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Ideal for: Sports & Leisure  
Those who Irrigate • Intimate Moments

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\* Actual size Select Minuet

To obtain your FREE sample of the Select Convex, Select Affresh pouches or the Select Minuet Stoma Cap return this coupon to:  
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Name (Mr/Mrs/Miss/Ms): .....

Address: .....

Post Code: .....

Select Convex Closed Pouch (please tick)

☐ Maxi ☐ Standard ☐ Mini

Select Affresh Closed Pouch (please tick)

☐ Maxi ☐ Standard ☐ Mini

\*Select Minuet 10-40mm ☐

Select Minuet Plus 10-55mm ☐

Please state your preferred film colour (please tick)

☐ Clear ☐ Opaque Stoma Size: ..... mm



BCA12/06





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

## Readers Writes

### Dear Editor

As the Colostomy Association celebrates its first birthday, I too will be celebrating as this is my first year with a colostomy. I had an emergency operation on December 14th 2005. I do look forward to receiving Tidings as I did not realise that so many people had stomas, or that it can happen to children so young.

I am 75 years old. It took me a very long time to come to terms with my colostomy and I had a few mishaps at the beginning. Then I received my first copy of Tidings and read of the thousands of people that also had stomas. I finally realised that it was not something that just happened to me.

When I first came out of hospital, I had a nurse call on me twice a day to see that my bag was changed and my stoma was cleaned. Then, after a while, when I could replace my bag and base plate on my own I had no one to turn to except the magazine, which I found very helpful and still do. I look forward to the winter issue of Tidings.

Yours faithfully  
D.H.L.

### Dear Editor

I had my colostomy formed on November 3rd 1994. As it was for a reason that I have never seen talked about in any of the magazines such as yours, I felt I must write. There must surely be other people who have – or will – experience the problem I had.

I had a rectopexy on January 1st 1989. To explain for people who don't understand this term, I had a prolapsed rectum and this operation was done to rectify it. Unfortunately some of the nerves around the anus were damaged and for five years I endured great difficulty in defecation: everywhere I went I had to carry enemas – needing to use them most days followed

by washouts. This was very stressful so I went ahead with a colostomy and have never regretted it.

Initially I had problems which were very upsetting, but, with the help of my lovely stoma care nurses, these were soon resolved. My quality of life was, and still is, so much better.

I have never had a problem from odour when disposing of bags. I wear a two piece and the bags I use can be completely sealed. I put all used bags into a plastic bag which I tie up and have never had any trouble putting them with my other rubbish.

I hope this letter may be of some help to other ostomates. We do not have a support group in the Grantham area and at nearly eighty-three I do not feel able to start one.

Yours sincerely  
S.B.

### Dear Tidings

Am I the only colostomate who would like to have larger bags?

The fashion trend nowadays appears to be for smaller and smaller and more discreet bags at the cost of functionality. If my stoma decides to work during the night or during the day, when it is not possible to change the bag as frequently as I need to, an accident occurs, which would, if a larger bag was available, be avoided.

Unless we colostomates let the manufacturers know about this, the trend will continue. If it is something that affects you, please do write to your manufacturer/supplier and let them know.

Yours sincerely  
M.P.

### Dear Editor

After losing my mother and my husband within four weeks of one another, at the end of 2002, life was at a very low ebb. I was just picking myself up again when, at the beginning of 2005, I was diagnosed with bowel cancer at the age of sixty-six. After an intensive course of chemotherapy and radiotherapy, I had my surgery in May 2005 resulting in a permanent colostomy, then a further course of chemotherapy. I have now just completed my first year check ups and am pleased to say everything went well.

No one can prepare you for the mental ups and downs you go through, but with an excellent surgeon, nursing staff, specialist nurses and the support of family and friends life does get better and you learn to live with your stoma.

I am grateful for all that was done for me and look forward to a brighter future. I have joined a computer course to bring me up to date with modern technology, rejoined my yoga class and am now enjoying my gardening again.

I find the Tidings magazine a great source of inspiration: reading about other people's experiences and the positive attitudes of colostomates. May I wish your association every good wish – and keep up the good work

Kind regards to All  
B.C.

### Dear Editor

A very big thank you for your feature on travel insurance. After having a colostomy operation I felt that "travel-wise" no one wanted to know me. I accepted that places like America might now be off limits. The only insurance I had been able to obtain was for single trip only. Saga had provided me with just that much cover, but then I found out that their policy had completely changed. Thanks to your article I now have a comprehensive annual policy with "Free Spirit".

Many thanks  
P.K.

*Our Head Office in Reading (0118 939 1537) has details of this and other insurance companies that our readers have told us provide a "good deal" for ostomates. Ed.*

### Dear Editor

I receive Tidings every quarter and like to read it. There are a lot of hints that are very easy to understand too. I had a colostomy in 1967 and I don't regret it. I was only twenty-seven with a young wife and two children. My wife was very good, looking after me during the operation and afterwards, and she also helped me with changing the bag. Four years after the operation we had another son. In those days I had a few accidents as the bags were made of rubber. Then one day I went for a check up and the stoma nurse put me on a different appliance. While my wife was alive we went on different holidays and never had any problems, thank God. I go swimming, dig the garden and enjoy myself. Now I change once a day and it takes about ten minutes or so. I use disposable bags.

I was very pleased to have the operation done and lead a healthy life. It is now thirty-nine years since I had the op. I always thank the people who helped me and my late wife for everything they have done. I have never written to anyone about it before.

Yours  
S.J.F.T.P.



Dear Editor

I travel a lot and, having a colostomy, the current security restrictions can cause problems at airports. In August this year, just after the new restrictions on liquids, creams etc., I flew to Canada. No problems at Manchester, but on travelling back from Vancouver, after checking in our cases, I was told that I would have to go back to check-in to put my colostomy barrier cream and aerosols in the hold. I refused and then spent ten minutes with two supervisors in a packed security area explaining the situation. Eventually sense prevailed and I was allowed through.

So I was delighted to receive the new travel certificate in several languages. This, along with a copy of a letter from my doctor, is now displayed in the plastic see-through part of my colostomy carrier bag.

In early November we travelled to Nice in France - again no problems at Liverpool airport. However, on returning, even though I showed the certificate in French and my doctor's letter to the security personnel, they refused to let me through and called the Police - unbelievable. After a long conversation in French between the security and the policeman, they just shrugged their shoulders and let me through.

I hope I was just unlucky. The certificate is excellent but may need amending to include creams and aerosols on the next print run. Also is it possible to ask the relevant government department to advise airport security in both Britain and other countries about the products that are necessary for colostomates when travelling?

Off to Spain in January so must be third time lucky!

Thanks once again for all your support  
T.C.

*In November security procedures at airports were changed. At the time of going to press, passengers are allowed to carry a limited quantity of liquids (up to a maximum of 100ml per container) in a transparent re-sealable bag (eg ziplock) that should fit into hand luggage. The bag should be closed and items fit in comfortably. Sufficient medical equipment for the journey can be taken aboard in hand baggage. However, as the situation is constantly changing, it is a wise precaution before leaving home to check on the website [www.baa.co.uk](http://www.baa.co.uk) or contact the airport direct for advice on the current situation. Ed*

Dear Editor

I have had a colostomy since 1999, not due to cancer, but still a major upset in my life. My stoma is very unstable and I have not always had an easy time. This year in August it was my sixtieth birthday. My wonderful husband, Michael, and I decided to travel a bit further afield, to visit my sisters in Australia and the USA. Each trip would last a month, so we looked into everything I would need while away.

The delivery company I was using was going to charge me to have my colostomy supplies sent out to each country. However, at a roadshow I found another company, called Fittleworth, who didn't charge. After changing to them and just one delivery, I needed to have things sent out to Australia. They took my order in July and within a week it had arrived at my sister's home - a real success story.

We had a lovely time and came home the middle of September. I used the same procedure to have my equipment sent to America. Once again the delivery company was very helpful, but it was not quite such a success as Australia. The order was sent three weeks before we were due to leave, but we didn't hear from my sister to say it had arrived. Eventually after a number of phone calls my package was traced to customs somewhere in the USA. The Food and Drug Agency had refused to accept the box as they did not know what it contained and it was being sent back to the UK!

We had to quickly go out and buy a case to take all of my equipment with us. The supplies I had sent in advance didn't arrive back in this country until after we got home. It took one week to get to the USA and five weeks to come back! However, it hadn't affected our holiday; we had a wonderful time but could have done without the hectic few days before we went.

I just thought I would let you know that the supply company I use is extra special. Keep up the good magazine.

Yours sincerely  
I.C.

## Readers Writes

Dear All...

*Thank you for your letters. Please keep them coming.*

*In the interests of confidentiality we will publish only your initials, not your full name, unless you give us permission to do so.*

*Do write to us with any questions you may have or to tell us of your experiences. We would like to hear all your views.*

Ed





## Poets Corner...

Bill wrote this poem during his stay in hospital awaiting an operation to remove his colon.

### A Friend at My Side

I'm reluctant to sever the tie,  
But I think from now on it's goodbye,  
We've reached an impasse  
And we're parting at last,  
Without sadness, a tear or a sigh.

You are being dispatched to the tip  
And replaced by a friend at my hip,  
You're no longer my chum  
Just a pain in the bum,  
So goodbye, au revoir, toodle-pip.

I shall have a new mate at my side,  
A change I shall take in my stride,  
A replacement for you,  
But a friend good and true  
A companion well trusted and tried.

You are being confined to the sluice,  
No thought of reprieve or a truce,  
With scissors and knife  
You'll be out of my life,  
Discarded and no further use.

Many times I've sat in dismay,  
To consider the news of the day,  
But each day I ponder  
The sittings get longer,  
And my life is just passing away.

So farewell to my trouble and strife,  
You've a date with a man and his knife,  
When you're a thing of the past,  
I'll have freedom at last,  
A chance to continue my life.

W. J. Hall (March 2004)

Angie had her colostomy in February of this year and wrote a poem about it a few months ago. She would very much like to share it with other readers of Tidings.

### This Blob

You would never guess  
By looking at me,  
But I've just had  
A colostomy.

It's called a stoma  
And sits on my side,  
Does its own thing  
That can't be denied.

Like a wilful child  
Has a mind of its own,  
It will shout out loud  
Or quietly moan.

I'll treat my stoma  
With loving care,  
'Cos my life with it now  
I must always share.

There will be bad days  
When I feel a bit low,  
I need time to adjust  
Let my confidence grow.

This cherry sized blob  
Has no panache or poise,  
When it's most inconvenient  
It makes a noise.

When it needs attention  
It will use its voice  
Then to run to its aid  
I have no choice.

But I'm very thankful  
For my colostomy,  
It's given me new life  
And set me free.

Angie Dean



## 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 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
- ☐ I have completed the Standing order form on Page 46  
(please complete the standing order form overleaf)
- ☐ Please tick here if gift aid applies to your donation (see overleaf for details)
- ☐ Please tick here if you require a receipt acknowledging your kind donation

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

# Donations & Standing Order Authority

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

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

Title: \_\_\_\_\_ First Name: \_\_\_\_\_ Second Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Postcode: \_\_\_\_\_

Tel: \_\_\_\_\_ Email: \_\_\_\_\_

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

To the Manager (Bank or Building Society) \_\_\_\_\_

\_\_\_\_\_

Address: \_\_\_\_\_

Postcode: \_\_\_\_\_

Name(s) of Account Holder(s) \_\_\_\_\_

Account No: \_\_\_\_\_ Sort Code: \_\_\_\_\_

## Please pay:

\_\_\_\_\_ NatWest Market Place Reading Branch

\_\_\_\_\_ 13 Market Place Reading RG1 2EP

Account Name: \_\_\_\_\_ Colostomy Association Ltd

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

The sum of: \_\_\_\_\_ £

Amount in words: \_\_\_\_\_

Date of first payment: \_\_\_\_\_

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

Name: (IN CAPITALS) \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## I want the Colostomy Association to treat:

The enclosed donation of £ \_\_\_\_\_ as a Gift Aid donation

Signature: \_\_\_\_\_

*giftaid it*

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

Registered Charity No: 1113471





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Send me: ☐ Closed ☐ Drainable

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## Recycling Appeal

Don't forget, if you have any old mobile phones or printer cartridges they can be recycled to raise money for us. You can phone us and we will send you a freepost envelope or contact recycling appeal direct on [www.recyclingappeal.com](http://www.recyclingappeal.com) or 08712 50 50 50

## Everyclick

[www.everyclick.com](http://www.everyclick.com) is a new search engine that helps charity. All you need to do is sign in and register for the Colostomy Association. Whenever you search the web you're raising funds for us, with no charge to you or to us. So make everyclick your homepage today!

## Ostomy Penpals

Would you like a penpal? Then log on to [www.ostomy.evansville.net](http://www.ostomy.evansville.net) (run by Larry Trapp) and follow the link for penpals. You can choose a category e.g. colostomy, ileostomy, professional, carer. The site is based in America but people from all over the world log on.

Larry writes: My desire as webmaster is to help you find fellow ostomates to compare notes. Please remember all ostomates and stomas are different, and what is appropriate for one individual may be completely inappropriate for another.

## Plant Sale

Mr and Mrs D Ashe are holding a plant sale on 26th May 2007, outside their home in Cranleigh Drive, Brooklands, Sale. So put this in your diary now. All money raised will kindly be donated to the CA

## The Customer Management Journal's 'National Customer Service Awards 2006

Congratulations to Securicare for winning the Customer Service Team of the Year, Healthcare and Pharmaceutical category, 2006.

Well done from all at the CA!

## SMALL ADS

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

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



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

## Tidings is your Magazine

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

## Colostomy Association

15 Station Road  
Reading RG1 1LG  
Tel: 0118 939 1537 Fax: 0118 956 9095  
E-mail: [cass@colostomyassociation.org.uk](mailto:cass@colostomyassociation.org.uk)

## Visit our new look web site

[www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk)

## Helpful Groups & Organisations

- Macmillan Cancer Support  
Information line  
0845 601 6161
- ia (The Ileostomy & Internal Pouch Support Group)  
0800 018 4724  
(freephone)
- Urostomy Association  
0870 770 7931
- National Association for Colitis and Crohn's Disease (NACC)  
0845 130 2233
- National Advisory Services For Parents of Children with a Stoma  
01560 322 024
- National Key Scheme (NKS) From RADAR  
  
Please write to;  
RADAR, Unit 12,  
City Forum, 250 City Road,  
London EC1V 8AF  
  
For a National Key Guide and Toilet Key send a cheque for £13.50 (incl p&p) stating that you have a Disability/Colostomy or for just a key send a cheque for £3.50 (incl p&p) alternatively contact your local Council.
- Beating Bowel Cancer  
020 8892 5256
- Red Cross  
UK Office switchboard  
0870 170 7000
- Bowel Cancer UK  
London 020 7381 9711  
Edinburgh 0131 225 5333
- Colostomy Association  
Freephone:  
0800 587 6744 or 0800 328 4257