colostomy association

Tidings

Summer 2008 Issue 10

Dedicated to Colostomates and their Carers

Tidings
Magazine
Anniversary
issue
10
YEARS
1998-2008

Tidings
FROM THE BRITISH COLOSTOMY ASSOCIATION

New appointments at BCA

Alan A Mayor

Howard Jones

Greetings from the Editor

Cathy Richards

From other Organisations

inside...

Colostomates share their experiences
plus...all our regular features

Stoma Care Professionals write about...
- rectal pain


Tack & Adhesion
Flexibility
Absorption
Erosion Resistance
Ease of Removal

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Tidings
Dedicated to Colostomates and their Carers

The Colostomy Association is a charitable company limited by guarantee (Registered Charity No: 1113471) that represents the interests of Colostomates and other ostomates. We provide support, reassurance and practical information to anyone who has or is about to have a Colostomy.

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inside
this issue of Tidings

Dear Readers..

Hello and welcome to the summer edition of Tidings. We hope you find our usual blend of professional information, hints and tips, friends’ experiences and articles interesting.

As you will have gathered from the front cover, Tidings is celebrating its tenth birthday, we are fortunate to have memories from our first editor Cathy Richards who looks back at those early days. My stoma was in its infancy when I first met Cathy and although she states that she “had the privilege of being the first editor of Tidings” I believe it was the Association that was privileged to have Cathy. If any of you can remember Cathy I would love to hear from you.

From Tidings’ slim beginnings we now boast a whopping forty-eight pages and its success is down to you our readers, for without your experiences, both good and bad, your hints and tips, help and advice we wouldn’t have a readership now in excess of twenty thousand each quarter.

Our editor Rosemary Brierley, has been the driving force behind Tidings’ appeal and is the person responsible for the magazines’ empathetic feel - something that comes across as you read through the pages. After two years of hard work and effort the solid foundations she laid in the beginning are now being built upon by the editorial team. Rosemary, after much long and hard debating has decided to step down as editor to allow in her own words some “fresh ideas” to come forward. Rosemary will now be concentrating on her expanding family and attending to a continuing health problem. We won’t be letting Rosemary go that easily as we intend to put her in the spotlight in the next issue of Tidings. In the meantime, the Trustees, the editorial team and the staff send their love and best wishes to a very special lady.

As you can imagine, finding articles for Tidings is a full time job and we are always looking for new ideas to help fill the pages so, if you have a passion for writing or perhaps you are already involved in copywriting or have been in the past and would like to join the editorial team, please contact the office on 0118 939 1537.

Another event that will soon be upon us is our 2008 National Conference at Reading University. With so much to see and do in and around Reading it will be a fantastic day out, not only for our membership but friends and family as well.

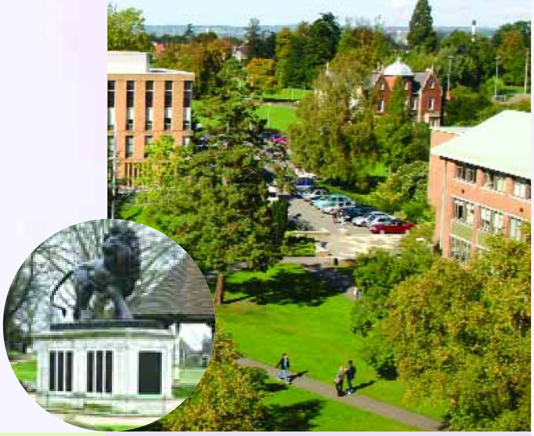
Throughout my stoma’s fourteen year life I have benefited from some great team work. I had a great team of surgeons, great help from my Stoma Care team, and I work with a great team of voluntary visitors back at the University Hospital of North Staffordshire. This edition of Tidings is no exception; with Rosemary away basking in the sun I was asked to temporarily take over the role of editor, but I have to put my hand up and say a big thank you to our editorial team who have done the lion’s share of the work, and once again got this great magazine out to our readers. Thanks team.

Ernie

Ernie Hulme
Temporary Editor

colostomy association

The Colostomy Association National Conference 2008


Courtesy of Reading University

Much interest has been received following the announcement of our 2008 National Conference in the Spring edition of Tidings. Details are still being finalised as we go to press and the following information should be viewed as provisional for the time being.

Conference Venue Reading University

The following companies have confirmed attendance at the event and they will be bringing a wide range of examples of their products for you to view and to discuss with their representatives :-

- Braun
- Bullens
- CliniMed/SecuriCare
- Coloplast
- Convatec
- CUIwear
- Dansac
- Fittleworth
- Hollister
- Homecare
- Oakmed
- Ostomart
- Peak Medical
- Pelican
- Salts
- White Rose

We will also have presentations taking place in the attached Theatre during the course of the day and these will include sessions on the role of the Pelican Centre, Reversals, Exercise and a Fashion Show with clothes from a high street store.

The Conference will run from 10 a.m. until 4 p.m on Thursday 11th September and you will be able to visit at any time during the day. A map of the location, a final agenda for the presentations and a final list of companies attending will be sent out along with your ticket two to three weeks before the event. We are hoping to run a shuttle service from the railway station in Reading for any visitors coming by rail.

Tidings
Dedicated to Colostomates and their Carers

If you would like to attend the Colostomy Association National Conference 2008 - please complete the form below and our mini questionnaire entitled - About You (the information provided will help us get to know our membership better - many thanks in advance) then return your form to:-

National Conference, Colostomy
Association, 2 London Court, East
Street, Reading, Berkshire RG1 4QL

The Colostomy Association National Conference 2008

Date: Thursday 11th September, 10am-4pm Venue: Reading University, The Palmer Building

Please fill in the form below with (BLOCK CAPITALS) delete where appropriate and RETURN to:-
National Conference 2008, Colostomy Association, 2 London Court, East Street, Reading, Berkshire, RG1 4QL

I/We would like to attend the Colostomy Association National Conference at Reading University on Thursday 11th September 2008.

Name: (Mr/Mrs/Miss/Ms) ____________________

Address: ____________________

____________________ Postcode: ____________________

Telephone Number: ____________________ Email addresss: ____________________

No of tickets required: ____________________

Names/s of other people attending with you: ____________________

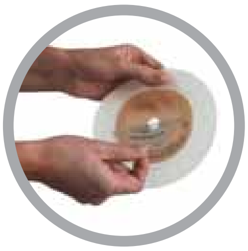
____

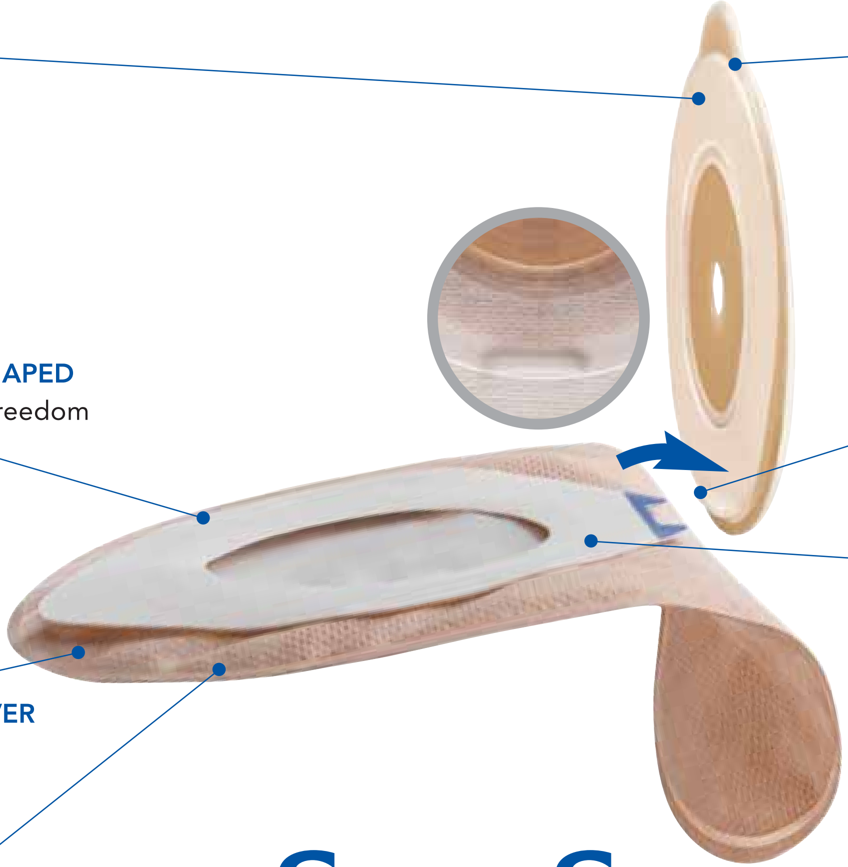
About You: Mini Questionnaire - (Please fill in your details and tick the appropriate box - thank you.)

Date of Birth: ____________________ Male: ☐ Female: ☐

Type of Stoma: Colostomy: ☐ Ileostomy: ☐ Urostomy: ☐

Cut along the dotted line and send to the return address





A passion for life...
recovery after colorectal surgery

Bev Whiston - Back on the bike - July 2007

It is now the first anniversary of my illness and subsequent operation and having made a full recovery and returned to my previous passion of mountain biking and skiing, I have decided to set down my thoughts on paper.

In January of 2007, having just returned from an Antiques Fair at Tatton Park, I went down with a nasty flu bug, and as a very fit 62 year old I usually throw off such infections very quickly, but this one seemed to go on for two weeks. As the days passed I began to feel there was something very wrong – I began to feel extremely ill and one evening said to my wife "I think there is something seriously wrong with me". That night when paying a visit to the bathroom I passed out and my wife found me in the laundry basket which frightened her very much. She phoned the doctor and a lovely young woman came to see me – I was in bed now. The doctor took one look at me and I could see the concern in her eyes. After a few tests, including a blood test, she phoned for an ambulance and I was admitted to the Royal Shrewsbury Hospital as my potassium level was the lowest she had known. This can be very dangerous causing irregular heart rhythms, and I found myself on the cardiac ward, hooked up to a heart monitor and intravenous drip to replace the lost potassium. The next day the nurses said I was looking very much better and indeed I felt much better but a general surgeon said he wanted to find out why I had been losing all this potassium. After many questions on my previous state of health, he gave me the impression he was unsure of the cause of the loss but the only clue lay in the one symptom I had had, which I had put down to IBS.

I stayed on the cardiac ward for several days and was assured that my heart was in good shape, a series of tests, the first being an ultrasound of my lower abdomen – stomach down to groin – this was a very thorough test but did not show anything untoward apart from a small cyst on one kidney – so far so good! A few days later I had a CT scan and since I had never been in hospital in my life before this was quite an interesting procedure. The scan did not last very long and when it was finished the technician came from behind the protective screen and said to me "What do you do for a living, Mr Whiston?" It was then I knew something was very wrong; it is difficult to explain how I knew, but it was something in his tone. I returned to the ward and subsequently had a visit from a young registrar who informed me that I had a large mass in my lower rectum and would require major surgery. It seems my intuition was correct. I seem to recall it was a surreal moment for me. However, when I had time to reflect on what had been diagnosed, I realised I was seriously ill.

At this point I was transferred to the colorectal ward under the care of Mr Quayle who told me in no uncertain terms that I had a very large tumour in my rectum and was 100% certain it would be cancer. Further tests including x-ray, sigmoidoscopy, and an MRI scan confirmed the diagnosis. I was then told the operation would consist of removing a small amount of colon, all of the rectum and my back passage, but it was to be preceded by a course of chemotherapy and radiotherapy. However, they were concerned that during the long treatment I ran a risk of a bowel blockage, so a keyhole operation was set up to form a temporary colostomy. Whilst I was on the operating table my consultant had another good look at the tumour and found it was not cancer but a very large polyp. Someone had just given me my life back! As a result of which there was no need for chemotherapy or radiotherapy, and I was instructed to go home to recuperate for three weeks and to then return for the major operation.

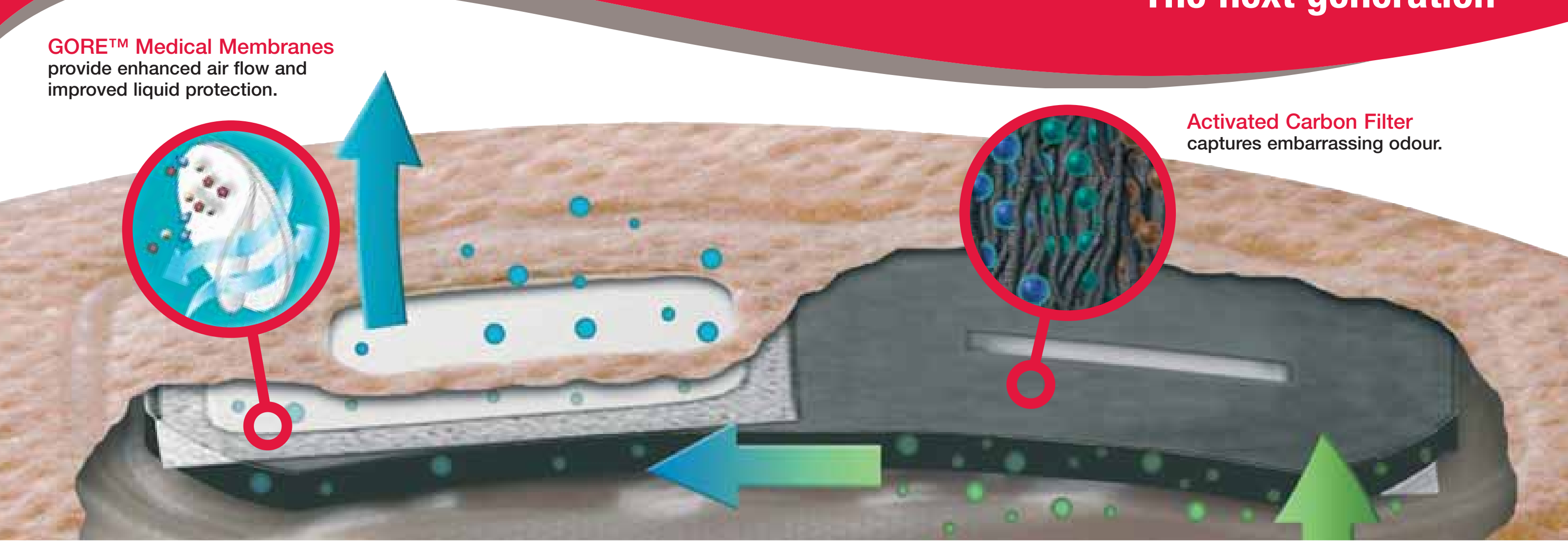
Whilst I was at home my first consultant retired and I was transferred to Mr Hunt. An appointment was made for me to attend his clinic. I remember the day very clearly; my wife and I sat in a room waiting for him. When he came in I was immediately struck by his large presence, both physically and intellectually. After a short discussion and rectal examination, he said he could do the operation and save my back passage and eventually re-connect me. Things were now looking very much better. Here was a man I knew I could trust, both from a medical and a personal standpoint. I was now going to be looked after by a brilliant man.

I returned to hospital two weeks later and underwent a long operation to remove this large polyp (1½ grapefruit in size) which was 100% successful and seven days later I was told I could go home, but a bladder infection kept me in for another 6 days. I came home on the 9th April 2007, and started my convalescence. My stomach felt like I had been run over by a bus and I thought I will never ride my bike again but Mother Nature is rather wonderful and not many weeks later I was walking a few yards, and by July 1st I was starting to ride again. Another visit to Mr Hunt's clinic confirmed that the histology showed my polyp was totally benign, which considering the size of it was a small miracle! By the autumn of 2007 I was climbing the Shropshire Hills with my bike as though I had never been through the experience of that illness at all.
I still have my stoma and continue dialogue with Mr Hunt about reversal. I have not come to a decision. My stoma is very predictable and does not impede me in any of my physical pursuits, and this winter I have just returned from two weeks skiing with no problems at all.

I would like to mention the wonderful nurses and doctors on Ward 25 and especially Mr Hunt and his team, and the colorectal nurses who have given me so much help and support. I could not have wished for a better team of people. God Bless them all.

And finally thanks to my wonderful wife Stella – I am so lucky.

Bev Whiston



Update...

on new stoma care products and services

Two companies contacted us with details of stoma care appliances and services that have been introduced within the last few months:

Salts Healthcare has launched a new and improved range of stoma support wear. Called Simplicity, the unisex boxers and ladies briefs are not only made from a lightweight and breathable fabric that keeps the body dry at all times, they also benefit from antibacterial properties.

Simplicity Stoma Support Wear is made in two-way stretch fabric, which moves with the body and features ribbing on the front that gives secure pouch support as well as a flush finish that is virtually invisible under most clothing. The support wear also has a deep and high waistband which offers extra comfort and covers the pouch without preventing the stoma from working. What's more, Simplicity briefs have no labels to irritate you when you move and after washing they can be quickly dried in around thirty minutes.

The Simplicity boxers and briefs are available on prescription in the UK in black or white in S/M, M/L and L/XL sizes and form part of Salts' comprehensive range of accessories.

If you would like further information on our new range, need guidance on sizing or would like to place an order, please call Salts Freephone number 0800 626388 or visit www.salts.co.uk.

Pelican Healthcare is pleased to announce the launch of a new range of 2-Piece appliances which are available on prescription now*.

The Pelican Select 2-Piece range of products has been specifically designed to enhance comfort, whilst ensuring maximum security coupled with ease of connection.

Select 2-Piece is available in three pouch sizes of Mini, Standard and Maxi to suit your requirements with a silky soft fabric for comfort and discretion. The controlled flow filter is effective at reducing the risks of pouch pancaking and ballooning. Select 2-Piece base plates are available in two sizes: 50mm and 70mm dependent on your stoma size. The Select base plate is unique and extremely flexible offering you maximum comfort.

Please see our advertisement in this edition to request your complimentary samples or simply call the Freephone helpline on: 0800 052 7471.

*Not currently available in Scotland.

Information on new products and services received before 22nd August 2008 will be considered for inclusion in the next issue of Tidings.

Ray Goddard
Office Manager, Treasurer
and Trustee

Colostomates' Feedback...

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

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

Tidings

Dedicated to Colostomates and their Carers

Information from CliniMed

In the last Spring issue of CA Tidings there were a couple of references to FreeStyle Flushable as follows:-

In Readers' Writes, (page 39) a gentleman expressed his disappointment that the Symphony flushable stoma bag was no longer available. He thought the Symphony bag was more environmentally friendly than FreeStyle Flushable because the whole product could be flushed away. However, this Symphony product was not completely biodegradable. FreeStyle Flushable is environmentally friendly as the flushable part is biodegradable and the outer bag is recyclable with plastics. What is more the outer bag, being clean, can be disposed of at the user's convenience.

In the reply to one of the reader's questions about disposal, in Your Questions (page 12), it was stated that flushable appliances should never be put down the toilet on a ship or on an aircraft. CliniMed do advise that FreeStyle Flushable can be flushed down these toilets although, because the efficiency of different toilet systems varies, 100% flushability in all toilets cannot be guaranteed.

Christine Davies, a current FreeStyle Flushable user and frequent traveller, told us:- 'After a recent visit to Thailand on a long haul flight I would like to say how convenient, clean and simple to use Freestyle Flushable are especially on an aeroplane. I have also been on a cruise and found them absolutely a god send. I travel quite a lot to America as well and I would not go anywhere without them.'

If you would like more information on FreeStyle Flushable or you would like to try free samples please call the CliniMed Careline on 0800 0360100.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Penny Fitzgerald RGN, BSc
(Hons), Stoma Care ENB 216
Colorectal Nurse Specialist
Countess of Chester Hospital.

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

Rectal pain...

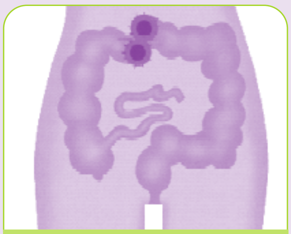
This is the second of two articles by Jill and Penny. In the Spring issue of Tidings they explained why ostomates may experience a discharge from their rectum. In this issue they go on to consider why for some ostomates rectal pain can be a problem and to explore some of the management and coping mechanisms that may be beneficial.

Like the previous feature on rectal discharge this article on rectal pain and the suggested advice are supported by a recently conducted survey of 150 people who shared their experience of living with rectal discharge and pain problems following surgery to form a stoma.

What causes rectal pain?

Pain can be due to a number of reasons depending on the type of operation you have had. In a Hartmann's resection or loop stoma the rectum is left in place while an Abdomino Perineal Excision of Rectum (APER) involves the removal of the whole of the rectum and anus (back passage).

Hartmann's Procedure



Loop Colostomy

Loop Ileostomy

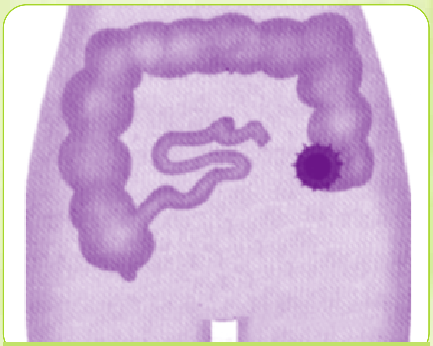
Hartmann's resection or loop stoma

If you have your rectum saved during surgery, pain in this region is usually due to a build up of mucus. It can make you feel like you need to have your bowels open, cause sharp shooting pains and/or low back ache, abdominal discomfort or a sensation of pressure in the rectum. By sitting on the toilet daily and gently bearing down as if you were to have your bowels open, you should be able to evacuate this mucus naturally. This reduces the risk of build up, which may lead to pain.

If the mucus won't come away naturally (some people say they don't have enough sensation in their rectum to push) a glycerine suppository inserted into the anus may help. You could discuss this with your GP who would be able to prescribe them if he felt it would be appropriate. It is a normal function of the body to produce mucus so it will not go away. However, some people report a significant reduction over time.

If the mucus leaks out in an uncontrolled way, this can make the skin around the anus constantly damp causing it to become painfully excoriated or itchy. Keep the area clean - using wet wipes if out and about or at work - and reapply creams or barrier films.

Abdomino Perineal Excision of Rectum (APER)



Abdomino Perineal Excision of Rectum or APER

If you have had your rectum and anus (back passage) removed and have a scar on your perineum (the area between the anus and scrotum or vagina) your pain may be due to different reasons from someone who still has their rectum in place.

If your surgery is recent you may find it very painful to sit down. This is because the area is still healing. Occasionally the scar is slow to heal and may need dressings when you first go home. Even if the scar looks well healed the tissue underneath can take months to repair. During this time you may find it easier to walk around and then lie on the settee rather than sit. Other people will find a particular chair more comfortable than others; try all the chairs at home and find the most comfortable. If it needs to be moved don't be tempted to lift it; ask for help from family or friends. If you are going somewhere and know the chairs will be hard take a cushion with you to sit on. An inflatable cushion is useful as it can be carried easily and used when needed.

You may experience perineal pain when you walk or bend because the scar feels tight. If you have had radiotherapy or your scar was slow to heal it may also feel thickened and inflexible. Sometimes the discomfort is only noticed when you have been advised by your surgeon or stoma nurse that you can start to resume normal activities and you find it difficult to lift your leg, for example getting into the bath or riding a bike. Try to get into a regime of daily exercise whereby you gently lift your leg or crouch until the point of discomfort and you will find it gradually becomes easier. If you massage the area regularly with a moisture cream it may also make it feel less taut. Regular bathing or showering can be helpful in reducing discomfort and helping to keep the area sweat free.

Phantom Rectum Syndrome

Some ostomates continue to describe a persistent desire to open their bowel or have pain where their rectum used to be - it's often likened to "toothache in the bottom". These symptoms are known as phantom rectum syndrome. The exact cause of the pain is unknown but it is quite possible that the nerves around the rectum get damaged during surgery.

The symptoms can be wearing as they may be very intense and persistent. A separate article is required to cover the problem in detail but hopefully by reading this you will be signposted to appropriate help.

The degree of pain varies: some people will find simple analgesics like Paracetamol or Ibuprofen eliminate the pain. However, those of you who have more extreme pain may find nothing will completely remove it and you have to use additional remedies to minimise the degree of discomfort.

If the pain is severe it is certainly worth discussing with your GP the possibility of a referral to a chronic pain team who may be able to offer more specialist treatments, for example a nerve block.

It is worth considering alternative therapies like hypnotherapy, yoga, acupuncture and reflexology. They may be successful in teaching you coping strategies to manage the pain.

Research has suggested visualization techniques can help to reduce the pain. You physically sit on the toilet and mentally go through the actions of having your bowels open.

Pelvic floor exercises and /or lying on your back and tilting your pelvis upwards may also help. It may be more comfortable to put a pillow under your bottom for support. Your stoma care nurse can show you how to do this.

Suffering pain alone is very debilitating and can make you feel isolated. Talk to your loved ones and health professionals if it is getting you down as sharing is often the first step in learning to manage the pain. Keeping active, visiting friends or taking up a new interest to divert your mind away from the discomfort can also be helpful.

This article has described some of the problems colostomates may face if they have rectal pain following surgery and stoma formation. We hope it has helped you to understand why rectal pain occurs and provided ideas for helping those who experience this type of pain to cope.

Please note any new pain should always be reported to your GP, surgeon or specialist nurse as he/ she will be able to eliminate the rarer more acute causes for pain, for example abscess or hernia formation.

Acknowledgements

Grateful thanks to:

- Coloplast Ltd for sponsoring this article in Tidings.
- Opus Healthcare who provided the financial support to allow the patient survey to be conducted.
- All the people who replied to the survey conducted through Charter Journal.

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

Dear Editor

Back in August 2005 I was diagnosed with a rectal tumour, which resulted in the inevitable colostomy and later, after radiation treatment and chemotherapy, an abdominoperineal resection.

As a result of the radiotherapy I experienced severe burning with huge blisters forming in the anal area, which resulted in an emergency admission to hospital prior to the removal of the tumour. Not unexpectedly the post operative wound took a fairly long time to seal and heal up.

However, after all these problems I am clear of any cancer and all the test results are good. For this I am extremely grateful but, and it is quite a but, I have yet to overcome the pain I have been left with, which prevents me sitting down for anything but the shortest time before needing to lie down and take medication.

I have tried various types of painkillers, including Durogesic patches and multiple other drugs in cocktails, with little effect, except to verify the side effects listed in the medication details. My pain consultant has discussed having pain blocking injections, but he is honest enough to admit there is only a twenty five percent chance of success. Apparently if they hit the exact spot the result is unbelievable, finding the spot is another thing. I must admit that other people's experiences of this treatment have put me off.

The various websites concerned with pain control all appear to agree that nerve pain, which I have, is complex and difficult to treat, and I wondered if any other colostomates could perhaps shed any light on the subject from a personal experience point of view, particularly how long this is likely to continue.

My most dramatic relief has come from acupuncture and using a Tens machine. However, reading on the subject indicates that it is as much about pain management as general relief, and of course this is influenced by one's state of mind. Trying not to be depressed when sitting for the shortest period of time results in very severe pain is not easy, and the majority of distractive interests are best performed sitting down.

Before my diagnosis I was very active and attended a health club a couple of times a week. I also used to spend as much time as possible in my garden - a hobby I very much enjoy. I desperately need to move on, get back to normal, and get my stoma out and about.

Any advice would be welcome.

Yours Sincerely
D.S. (Ms)

Dear Nurse

I am writing in reply to the gentleman who wrote to you on behalf of his wife who was suffering rectal pain. His letter appeared on the Dear Nurse page in the Winter 2007 issue of Tidings.

I had a colostomy in 2004 due to bowel cancer. I made a good recovery but suffered constant rectal pain. I was prescribed various rectal creams but nothing eased the pain and I had to resort to Tramadol, a strong pain killer. It was difficult to go out as I could not sit for long periods.

I told my consultant who organised a CT scan. He told me it was 99% sure that it was cancer. I was devastated but he was wrong and various biopsies showed no cancer cells present. It was found that the problem was due to scar tissue.

Gradually over a year the pain diminished and I was able gradually to ease off the painkillers.

I hope that the lady in question has now found the pain is easing.

Yours faithfully
J.R. (Ms)

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☐ 50mm (cuts to 35mm) ☐ 70mm (cuts to 55mm) Stoma size .... mm

Select 2-Piece Pouch (please tick one): ☐ Closed ☐ Drainable

Select 2-Piece Pouch Size (please tick one): ☐ Maxi ☐ Standard ☐ Mini

My preferred medical film (please tick one): ☐ Clear ☐ Opaque

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* The Pelican Select 2-Piece range is currently unavailable in Scotland.

Sarah with her inspiring daughter...

My story is similar to that of the young woman in the autumn 2007 edition of Tidings. I too have ended up with a stoma as a result of childbirth. However, I didn't have the colostomy straight away. This took another seven years to happen.

In May 2000 I gave birth to the most beautiful girl in the world. My world was complete after being told a year before that we would never have children. My husband and I were ecstatic at our new arrival although I was very unwell. During labour there were many complications and, as a result, I ended up with a third degree tear. As soon as my baby was born she was handed to my husband. I was too unwell to hold her, but I had done it and my miracle baby was here.

After nearly a year my bowel and bladder had not returned to normal, I was sure something was wrong and went to the doctor's to be told that I needed some corrective surgery. I thought that would be it. I would be well again. As time passed the incontinence became worse and started to affect my life at work and at home. I became very depressed. I went back to the specialist to be told I had irreparable damage to the bowel and needed to have more surgery. In 2002 I had an anal sphincter repair which, unfortunately, didn't work. I was no better and in fact was now on a concoction of drugs which included home enemas and antidepressants.

My husband and I started legal action to try and get some answers. I had legal aid for a time but after three years of fighting I had to return to full time employment which meant I lost my legal aid status. We no longer had the resources to fight our corner.

During this time I was only seen by my GP and no other specialists. Dealing with double incontinence every day was a living nightmare. I always knew a colostomy was on the cards. Anything would be better than my life now. I was very depressed and just wanted to hide away.

I nearly had a colostomy in 2005 but the surgery was cancelled as it was thought that I did not understand the full implications of the operation. Looking back I agree as I needed time to sort my head out and try to accept things as they were. The next few years weren't easy but we somehow got though it.

Illness of one partner is never easy to cope with at the best of times, but when you are both struggling to work out the future it can take you in different paths. Last year I separated from my husband and started to build a new life. I also asked to have the colostomy. I just wanted to be well again for my daughter. The surgery went ahead very quickly, in January 2008, which brings us to now.

The stoma nurses have been amazing and even gave Chloe Olivia a colouring book about people with stomas and questions asked by children. One of the questions was, ‘Will it blow off on a windy day?’ It has helped her to understand what is going on with Mummy and she knows I am getting stronger every day. She has looked at all of my kit with the wipes, the bags, the cream etc. She even awards me stickers on the kit bag each week.

I would say that my daughter has been my inspiration to recover and start living again. She has even learnt how to make me a cup of tea. When I was first recovering she would do this every day after school. She would lay the table for tea and make sure I had a comfy chair to sit on with a pillow. As it is not long since my stoma was formed I do suffer from noisy wind. Chloe Olivia finds this hilarious. She says she is very proud of me, which is lovely, and that she would like to take me to school!

“Life is different and there are lots of new things to get used to but most importantly life is drug free and I can now see a bright future ahead.”

When I enquired why she said that I would be the greatest “show and tell” ever. Everyone at school could meet “The Amazing Mummy with the Talking Tummy”!

Last week she saw my stoma for the first time. I had said she could but needed to wait until the post operative swelling had gone down. Then one morning Chloe Olivia was desperate for the toilet when I was changing my bag. I opened the door but kept my back to her. She then asked to see the stoma so I turned around and showed her. She said, ‘Ooh, it’s just a red blob. Does it hurt?’ I told her it didn’t and put the next bag over it. She waltzed out of the bathroom saying, ‘Thanks Mum for showing me. It’s okay.’

My parents have also been amazing and have supported me throughout all of this. They have spent many hours looking after me. My friends too have been fantastic, as have members of my church, coming in and doing household chores and shopping. I am very blessed and grateful.

When I read stories of people’s courage and the things they achieve post surgery it is inspiring but Chloe Olivia was worried about this. She asked if I was going to change and be a mummy that climbs mountains or sails the ocean. I informed her that I couldn’t do those things before and I am not going to do them now. It became a bit of a joke when I achieved each little milestone of recovery and even being able to win at scrabble, which I was unable to do before surgery!

“I would say that my daughter has been my inspiration to recover and start living again.”

Life is different and there are lots of new things to get used to but most importantly life is drug free and I can now see a bright future ahead. I don’t know whether that future will include someone new to share my life with or not, but I know with the strength of my family and love and support of amazing friends and my Christian faith, it will be a good one. Whilst I was in hospital I wrote down all my thoughts and fears and feelings about this new stage in life and I hope to put these together in a book to encourage others that you can spring back from a dark place, stronger and even better than before. Having a colostomy is not a disability, more of a chance to improve life for the better. For some people they say life begins at forty! Well, for me life is just beginning at thirty-four and it’s looking good.

Sarah Milner

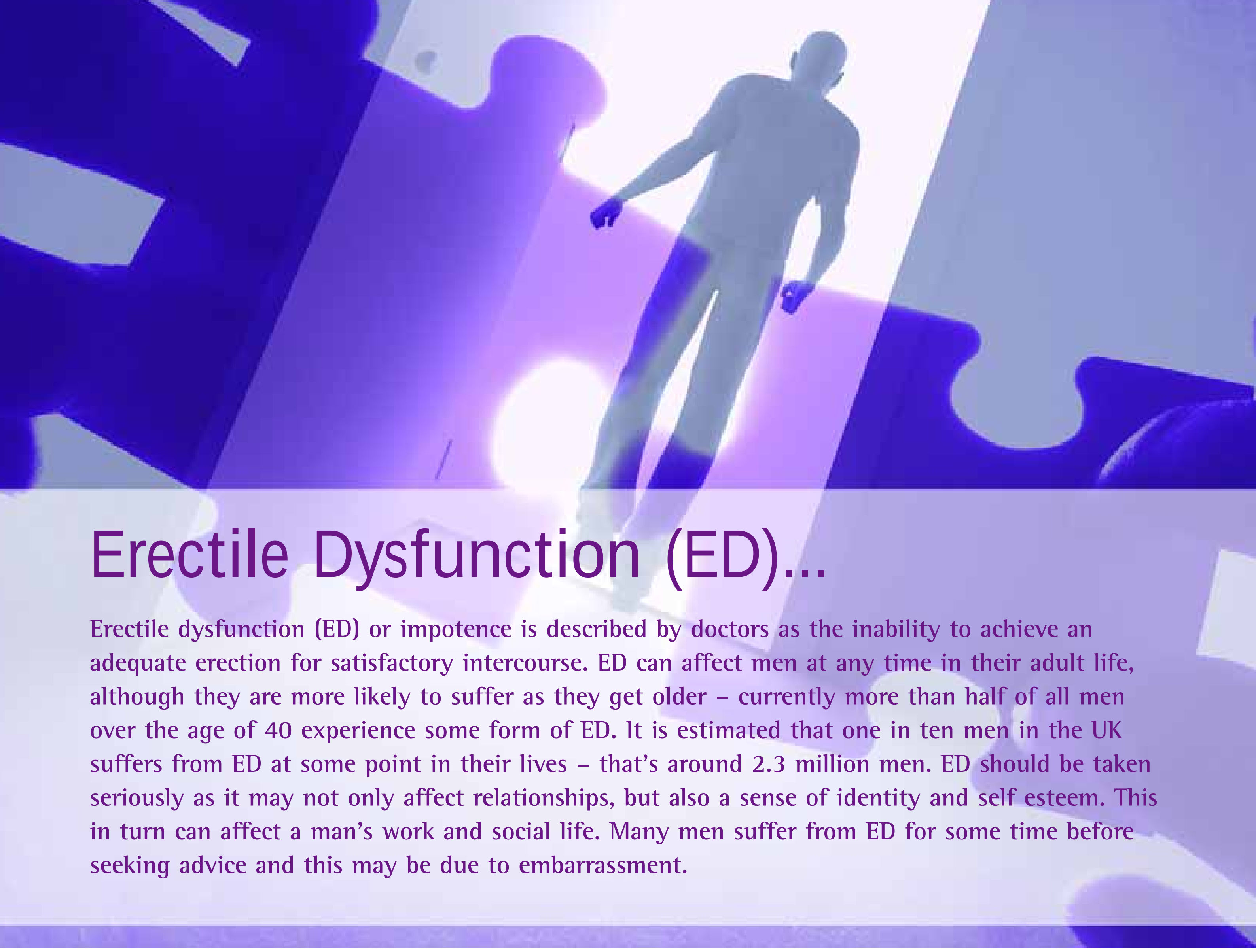
Tidings is your magazine...

If you have a story to tell like Sarah’s, an article, letter or any other item you would like included in Tidings, please post them to The Editor. Alternatively e-mail to our contact details below. We look forward to hearing from you.

Colostomy Association
2 London Court, East Street,
Reading RG1 4QL

E-mail:
cass@colostomyassociation.org.co.uk

Tidings
Dedicated to Colostomates and their Carers



Erectile Dysfunction (ED)...

Erectile dysfunction (ED) or impotence is described by doctors as the inability to achieve an adequate erection for satisfactory intercourse. ED can affect men at any time in their adult life, although they are more likely to suffer as they get older – currently more than half of all men over the age of 40 experience some form of ED. It is estimated that one in ten men in the UK suffers from ED at some point in their lives – that's around 2.3 million men. ED should be taken seriously as it may not only affect relationships, but also a sense of identity and self esteem. This in turn can affect a man's work and social life. Many men suffer from ED for some time before seeking advice and this may be due to embarrassment.

Tracey Virgin-Elliston
Stoma Care
Nurse Specialist

Getting and keeping an erection involves both physical and psychological stimulation. Signals from the brain tell the blood vessels in the penis to relax. This allows more blood into the penis, which becomes hard. The process can be affected by many factors, some of which are listed below:

- **Vascular:** When there is not enough blood entering the penis or staying there long enough to maintain an erection.

- **Neurological:** If messages from the brain are not received by the penis, the body does not produce an erection.

- **Hormonal:** Changes in levels of certain hormones in the body can be associated with ED. A low blood level of testosterone can lead to ED and problems with libido.

- **Medication:** ED can sometimes be a side effect of medicines for high blood pressure or depression. They affect the nerve impulses to the penis.

- **Psychological:** There are also psychological factors that can stop you from enjoying a rewarding sex life. These include altered body image, stress, anxiety and tiredness.

Major surgery on the abdomen/pelvis, such as that to form a permanent Colostomy, can cause ED. The Colorectal Surgeon will do his very best not to damage the nerves and blood vessels that control erectile function, but sometimes damage is inevitable, especially if the procedure is carried out for rectal cancer.

It is recommended that a wait of six months to a year after your operation is left before a referral is made. This would be to a Specialist Andrology

Clinic for review and treatment. These specialist clinics are usually led by the Urology Consultant and Urology Nurse Specialist. It depends where you live, however most clinics will accept referral from your G.P, Surgical Consultant, Stoma Care or Colorectal Nurse Specialists.

The following treatment information may be useful for when you discuss this matter in future. There are currently five types of treatment available. The most suitable one will be offered following individual assessment. According to the NHS guidelines, patients who have had stoma surgery are eligible for one dose of any treatment, free, per week. I know a number of patients report that this does not happen and they have had to pay for private prescriptions. However such operations are covered under the label 'radical pelvis surgery' and this information may be of help when talking to your G.P. One free dose per week does appear a little sparse, but this is based on evidence, which shows the average frequency of sexual intercourse in the 40 – 60 age range is once a week.

1. Oral Therapy

This has revolutionised treatment as most men find taking a tablet less embarrassing and intrusive than some of the other treatments. These drugs are known as phosphodiesterase type 5 (PDTE5) inhibitors. For these drugs to be effective you need sexual stimulation (foreplay) as well. They will not give you an erection spontaneously.

Viagra (Sildenafil) is swallowed about one hour before intercourse and it is recommended that it be taken on an empty stomach. It has been shown to have worldwide success with minimal side effects. However those on prescribed nitrate-based cardiac medication cannot take it.

Cialis(r) (Tadalafil) can be taken up to 36 hours prior to intercourse. It works by increasing the effect of one of the chemicals produced in the body during sexual arousal. Again it may not be taken by patients on some cardiac medications.

Levitra (Vardenafil) can be taken up to 30 minutes before intercourse; however the speed of erection varies with each individual and some men report achieving an erection 5 hours afterwards.

Uprima (Apomorphine hydrochloride) is a tablet that works differently and so may be suitable for patients who cannot take Viagra. It is dissolved under the tongue ten to twenty minutes before intercourse and improves the messages from the brain to the penis. These usually give erections within 10 – 20 minutes, however some men find they cause headaches, feelings of sickness or dizziness.

2. Injection therapy

These treatments have been available since the 1980's and have been used successfully since then. A number of men find the idea of putting an injection anywhere near the penis very off putting, but it is a painless procedure and most men succeed with practice.

Caverject, Viridal (Alprostadil, prostaglandin E1 or papaverine). The drug is injected into the side of the shaft of the penis and improves the blood flow by dilating the blood vessels. It often takes the expert advice of the Nurse Specialist and changes in drug dosage to get it right.

3. Muse (prostaglandin E1) therapy

This method has been available since 1998. A small pellet is inserted into the tip of the urethra using a small applicator, after emptying the bladder. The pellet dissolves and, after some rubbing to distribute it into the tissues, it produces an erection. Some men complain of pain and urethral burning.

All of the above are available on prescription and may be prescribed by your G.P., Oncologist or relevant hospital consultant.

4. Penile implants

These require further surgery to implant an inflatable rod or balloon into the penis. This can be inflated when an erection is required.

5. Vacuum devices.

A cylinder is placed over the limp penis and a pump draws blood into the penis causing an erection. This is maintained by placing a rubber ring around the base of the penis which may be left in place for up to thirty minutes. This is an extremely safe method and as of April 2002, some devices are available on prescription. The advantage of a vacuum pump is that it doesn't involve inserting anything into the penis, but it does need a bit of patience and practice.

I have only attempted to offer you a brief insight into available treatments. Not all of these are suitable for everyone so it is important that you are individually assessed by a specialist clinic. There they will discuss all of the suitable options, and any side effects in greater detail.

It is vital to involve your partner/s in this process as it affects them too. Do not become disheartened; it is well worth persevering as some of these treatments take a little while to conquer. Remember a good sense of humour is vital!

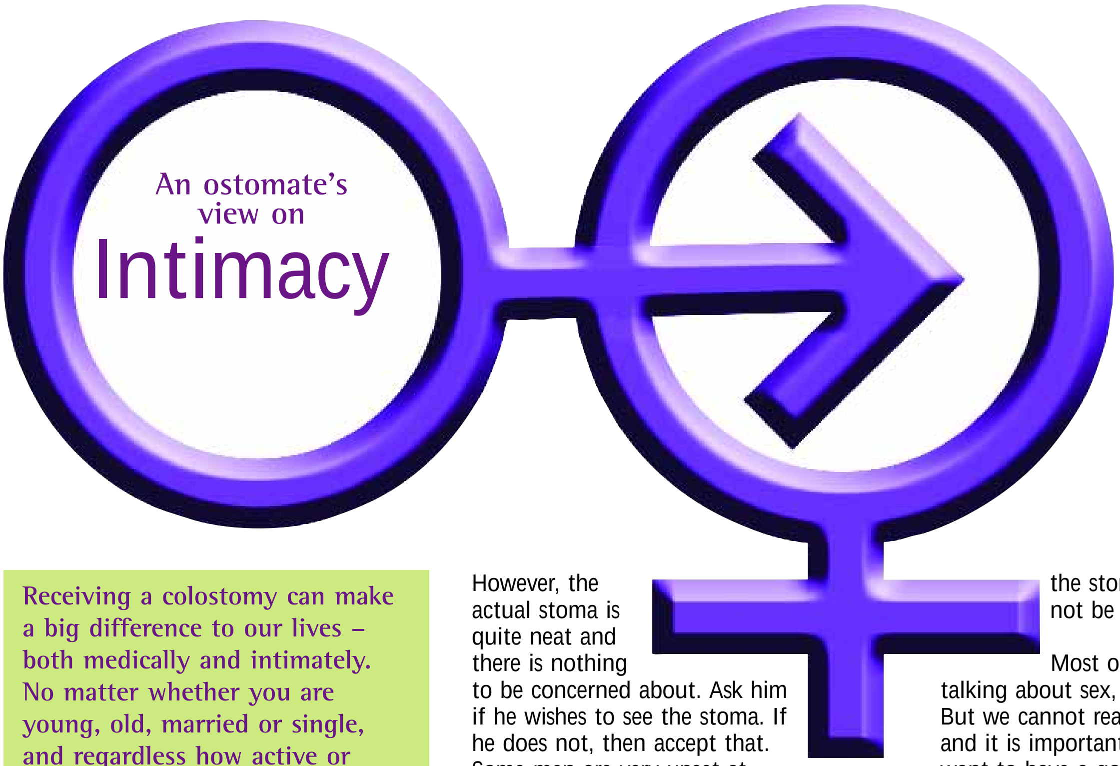
Further information and factsheets can be obtained from:

The Sexual Dysfunction Association
Suite 301 Emblem House
London Bridge Hospital
27 Tooley Street
London
SE1 2PR

E-mail: info@sda.uk.net
Helpline: 0870 7743571
(open Monday, Wednesday
and Friday (10.00am–4.00pm)
Web: www.sda.uk.net

An ostomate's view on

Intimacy



Receiving a colostomy can make a big difference to our lives – both medically and intimately. No matter whether you are young, old, married or single, and regardless how active or inactive your sex life is, a stoma is a major change. For you, as well as your present or future partner, accepting life with a stoma means accepting that change.

We may be embarrassed about our stomas or accept them as part of getting on with a new quality of life. We may worry about whether people can see or know about our colostomy pouches. At work or play we may get concerned about "it" making a noise, or giving out odour or even working at an inconvenient time. All these concerns we seem to cope with as we get more used to living with a colostomy.

The most frequently asked questions include: How will it affect my husband or partner personally? Will the intimate and sexual side of my life be affected? These are difficult questions to answer, as all of us are so very different in our personal lives. Some of us are lucky to have loving, caring, supporting partners, others may not. Some of our Colostomates may be on their own – ready to begin a new relationship.

We seem to be wary of what "it" looks like and how will I show "it" to him or her and will it affect my sexuality? Will I still feel feminine while wearing the pouch? How will I manage the act of sex? With my recent surgery will it hurt? Will the stoma work during the act of sex?

Taking each point in turn –

It will be an entirely personal choice to show your partner your stoma. It is possible that during your time in hospital or when you first returned home, your partner has helped change your pouch – so he already knows what "it" looks like. However, the actual stoma is quite neat and there is nothing to be concerned about. Ask him if he wishes to see the stoma. If he does not, then accept that. Some men are very upset at seeing any wound, so it is not necessarily the fact that it is your "bum on the tum" that he is saying "no" to.

Do not mistake your partner's concern for rejection.

At first your sexuality may be affected. You may not experience any sexual feelings for days, weeks or even months. You have had major surgery and your body will need time to heal. You may be afraid of pain or damaging yourself when you first make love. This is a time to enjoy that special cuddle. You may want to just touch, kiss or fondle your partner. There is so much caring and loving in being held, and holding your loved one shows that you still want them to be close.

Affectionate touching can be very positive and reassuring during your recovery. As in "courting days" there are ways that you can satisfy a sexual need of a partner. It is important that your partner knows how you feel and what you are thinking, so remember to talk over these feelings. Share your needs with your partner, continue to sleep together and tell your partner the most comfortable position for you to lie in.

It is hard to say whether the stoma will work during the actual act of lovemaking. Sometimes we worry about the possibility of odour and whether the pouch might come off..... If you have had a loving time leading up to the act, try to make time to put on a fresh pouch. You will feel clean and confident. The actual sexual position will make a difference too...so discuss with your partner the position that would give you the greatest confidence to let you relax during the act.

Intercourse will not harm the stoma and as long as you have put on your appliance securely, whatever position you choose, the stoma bag or the cover will not be affected.

Most of us have difficulty in talking about sex, especially after surgery. But we cannot read each others thoughts and it is important to show that you do want to have a good sexual relationship with your partner. Communication is a very important part of loving and caring.

Pretty nightwear is available and some even have a special pouch holder. For a woman, it can be important to wear feminine clothes and there is a wide range of underwear and nightwear items available. There are also pouch covers in many styles and materials from cotton to sensual satin. The Association can give you the contact details.

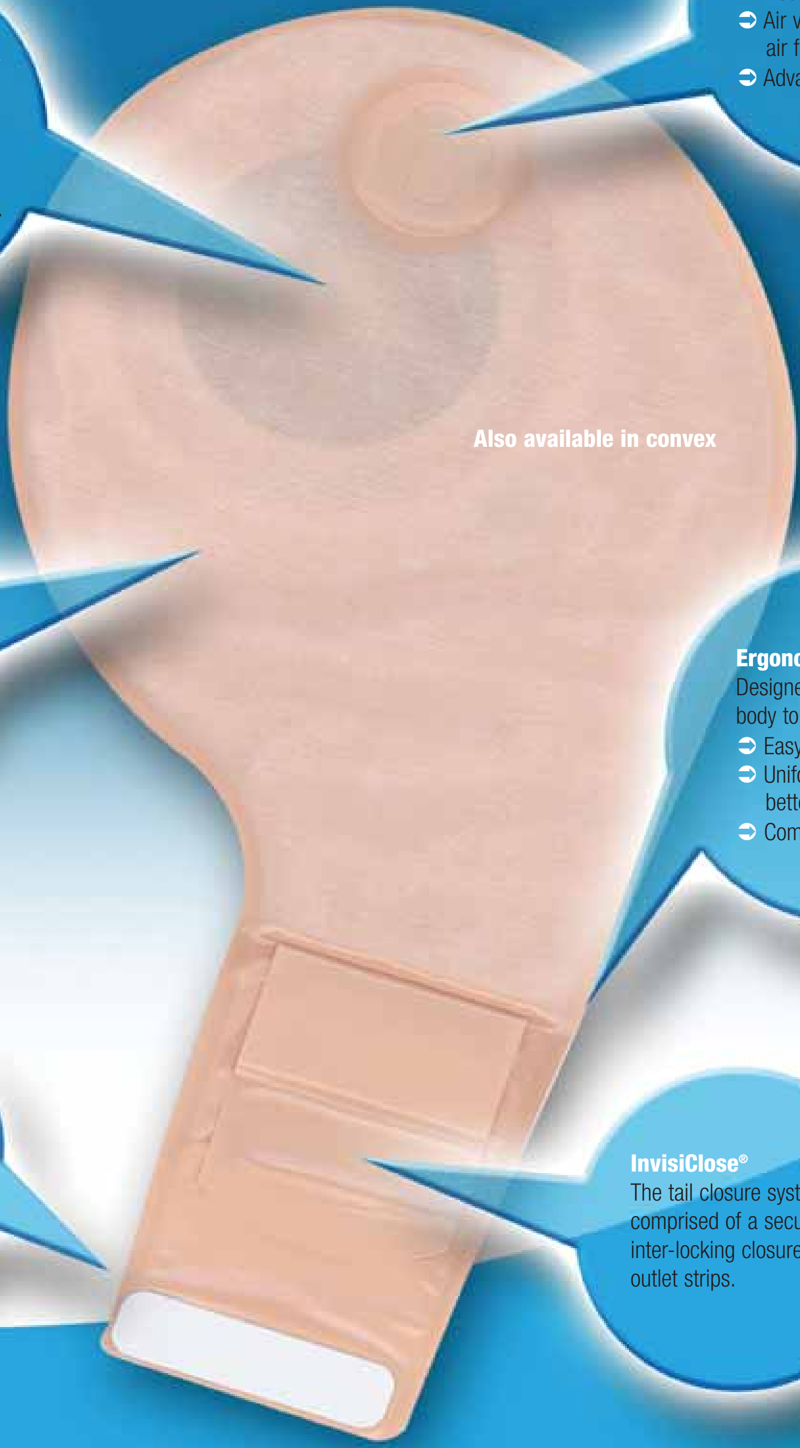
The single person who wishes to further a relationship may have the problem of "when do I tell that I have a colostomy". Since there is no right or wrong time to tell, you need to use your own judgement. It is always advisable to feel that you can trust them. It may be better to tell early into the relationship, prior to the first intimacy. If you have a good relationship then I am sure you will find that telling makes no difference to your feelings for each other. After all, you are the same person – personality wise. If your new found friend does not accept the stoma – then perhaps it is better to know now than further into the relationship. Experience tells us all that if someone cares about us, then they accept ALL of us, stoma included.

Whether you choose friendship, sex, marriage, or all three, remember that you are still the same person you were before the operation.

The Colostomy Association has volunteers who specialise in discussing in detail how to proceed with the sexual act to the benefit of both partners. You can call the Association in complete confidence and we will put you in contact with a volunteer.

Esteem®

Technology through understanding



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- Deodorizes
- Air vent to filter maximum air for more comfort all day
- Advanced membrane

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Soft fibrous backing available one side or two, which is easy to dry after a shower or swimming and reduces noise and friction.

Ergonomic Shape
Designed to sit centrally on the body to allow:
- Easy & natural drainage
- Uniform containment for better discretion
- Comfort

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Tail designed for natural drainage whilst seated.

InvisiClose®
The tail closure system is comprised of a security flap, inter-locking closure and outlet strips.

What more do you need...

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or email us at stoma.webcare@bms.com**

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Exercise Top Tip

Don’t hold your breath! Breathe out!

Have you ever thought about the advice given to patients following abdominal surgery not to lift anything heavy?

If you consider what is happening when you hold a weight in front of you, it is the muscles of the back (and particularly the lower back) which are preventing you from collapsing forwards, so why is it so important for your abdomen?

The answer lies in what else you do when you lift something. Usually, while you are lifting something heavy, or using unusual force in any direction, you will hold your breath. Holding the breath has the effect of increasing the intra-abdominal pressure, and it is just about the worst possible treatment for an abdomen temporarily weakened by surgery. This increase in pressure is precisely what will generate the force to find a weak spot in your abdominal wall and push something through it, giving you a hernia.

Sportsmen lifting weights in the gym are always taught to breathe out as they lift a weight; this prevents breath-holding, and avoids the risk of excessive pressure in the abdomen causing a problem. In the same way, if you aim always to breathe out when exerting force, you will be avoiding the pressure increase.

When you are doing “abdominal curls” to strengthen the rectus abdominis, the principal abdominal muscle on which your resistance to a hernia depends, think in terms of squeezing the air out as you curl, and it will come naturally to breathe out as you curl up. A useful reminder at all times is the “Grunt Rule” - if it makes you grunt, don’t do it!

Adrian March – C.A. Consultant

Disability Rights...

If you are experiencing difficulties at work due to health problems or disabilities, your first port of call should be your line manager. It doesn't matter if the problem is newly acquired or due to a deteriorating condition.

A good management team should be fully aware of the Disability Discrimination Act, what this means to their firm and how to support their staff along with their HR department.

Unfortunately, this is not always the case. The Act says that "reasonable adjustments" must be made for people whose health problems "substantially affect their day to day life." What this means in one instance may be quite different in another. It may be necessary to seek advice and this could come from a number of sources:

- The DDA helpline (Tel 0845 6046610) is run by the Disability Rights Commission and they can advise in individual cases.

- The Advisory Conciliation and Arbitration Service (ACAS) (Tel 0845 7474747) is another possibility. They can advise on general industrial relations, but when our investigator called it was felt this was not a particularly useful source for colostomates.

- ACAS suggested calling the Equality and Human Rights Commission who put callers through to a specialist depending on the help required. They are probably the best to give us guidance as colostomates.
Their contact details are
www.equalityhumanrights.com
Tel 0845 7622633 or 0845 6046610.
They say that because colostomy has an adverse effect on day to day life and is likely to last more than 12 months it does fit the criteria of disability as defined by the DDA. It also affects continence so is seen as a disadvantage.

- The Health and Safety at Work executive is available on 0845 3450055. They say that all employers must provide toilet and washing facilities that are suitable for everyone but they do not have regulations that refer to disabilities. That is the realm of the Equality and Human Rights Commission.

- Another useful area of support is via the Disability Employment Adviser at your local Jobcentre. The DEA can advise you or your employer of any "reasonable adjustments" that could be made, ranging from a change or reduction of hours, change of duties or role, useful equipment, in work support or even working from home.

- They can also inform you about the Department of Work and Pensions Access to Work scheme which provides specialist equipment, such as enlarged software or voice activated systems for those with visual impairments or lumbar support chairs.

The Access to Work scheme also, amongst other things, helps with support workers who take on parts of a job that the disabled person can no longer cope with, fares to work and Interpreters for hearing impaired staff.

As regards problems directly related to Colostomates, such as use of a disabled toilet and availability of lidded bins or sanitary bins which need to be emptied regularly, the first point of contact should be the employer. The company should consider providing a disabled toilet facility, if they do not already have one, as a person could "suffer substantial disadvantage" without one. The bins and their emptying should be covered under the "reasonable adjustments" aspect of the DDA. However, if the employer can't or won't supply them then an Access to Work case can be put forward.
The DEA can also turn to their Work Psychologist for extra advice and support. The WP can look holistically at the situation and see if anything else can be done.

In certain cases the Psychologist may be able to carry out a work based assessment at the place of employment to look at such areas as a change of role.
At the end of the day many people have been able to retain their job due to an enlightened employer's support, although in some cases this is not always possible, due to the severity of a condition, lack of a suitable alternative post or similar.
Even then the DEA may still be able to give advice on alternatives, such as voluntary or permitted part time work and general guidance on benefits.

Tidings..
the beginnings

Cathy Richards pictured with her husband Fred Richards.

Cathy was the first Editor of Tidings and kindly agreed to tell us about the early days.

Ten years ago I had the privilege of being the first Editor of Tidings. Communicating with our membership or Friends as we called them started off by sending Christmas cards each year and we always had great pleasure in choosing appropriate ones.

However, numbers were increasing all the time with more and more people contacting us for help or information about living with a colostomy. That year we thought we would do something different and after much discussion the idea of our own magazine was born. What an exciting (but daunting) project! This was to be the first publication written by colostomy people for colostomy people.

The idea was entirely due to Howard Jones, our then Chief Executive. Once it took shape Howard gathered a team around him. How did I become Editor? I think I volunteered! Trevor Partridge, who had been working with us for a number of years re-designing our literature was included and was to be responsible for setting everything up professionally, and what a good job he did.

BCA Logo

I can remember to this day when Howard Jones handed me a delightful sketch of a bunch of irises with a multicoloured ribbon around them. This was to be the logo, but what did it mean? The Goddess Iris was the personification of the rainbow and a messenger of the Gods. We used an Iris to bring you flowers, and a multicoloured ribbon to convey to you good TIDINGS and MESSAGES from BCA. So the title TIDINGS was born.

We started out with 4 pages that first Christmas, appealing to our many Friends for ideas to let us know what THEY wanted in a magazine. It would be a good medium for keeping everyone up to date with developments in the Stoma Care world and it was planned to include regular features from Health Professionals.

The help of all our staff at HQ was also enlisted and everyone put forward their ideas. Additional funding would be necessary and once this had been arranged we could go ahead.

It was not envisaged at this stage to take advertising, however, once the stoma pouch manufacturers saw the potential of Tidings they wanted to be included. The problem was solved by agreeing to include selected ‘flyers’ in the envelope then people could make up their own minds whether to respond or not. Of course this produced a logistical nightmare for a small office. Filling the envelopes which would include magazine and 4 or 5 adverts meant handling something like 60,000 items which had to be mailed in those first days.
We appealed to our local Colostomy Fellowship and three volunteers agreed to help. Co-ordinated by my husband Fred, our storeman, everything was delivered to our Stores in Reading and send out from there.

Then came my retirement in 1999. How would we get Tidings to our ’Friends’? Move the whole mailing operation to Devauden village hall! (A beautiful village in the hills of Monmouthshire where Fred and I retired). This was how your Tidings was sent out for a few years. We got very friendly with Cardiff Sorting Office and it was a common sight to see Royal Mail lorries pulling up outside.

Nowadays it is a much more streamlined and slick operation, everything done in one place, but what happy memories of all the places Tidings was mailed from - but that’s another story.

I get my Tidings through the post like everyone else. What a great publication it is. Each issue excels the last and it was an honour to have been involved. I feel sure that the other members of the original publication team join me in wishing Tidings many more years of success.

As we are celebrating ten years of Tidings Magazine...

Tidings
Magazine
Anniversary
issue
10
YEARS
1998-2008

We thought it would be a great idea to take you back in time to the first issue of Tidings...

◀ (Pictured left)

Over the next few pages you will be able to read clippings from Tidings Issue No.1 plus some topical news items from1998 and a quiz based on events that happened during that year... ▶

Tidings – Taking you back to 1998...

Tidings – Early Statistics...

- The first issue of Tidings was launched by the British Colostomy Association in 1998. It was the idea of Howard Jones CBE., AVA., the then Chief Executive.
- The first editor of Tidings was Cathy Richards.
- Tidings was written by colostomates for colostomates.
- The original issue was in the form of a newsletter, its size was A4 and included eight pages of text and pictures.
- The issue contained various news items, letters, write ups and some rather endearing characters.

Tidings Magazine Anniversary issue
10
YEARS
1998-2008

Welcome to 1998...

We hope you enjoy reading some clippings from Tidings Issue No.1 along with a mix of events from that year

Well, just what did happen in 1998...do you remember?

In the news...
Ol' Blue Eyes himself, Frank Sinatra, American popular singer and Academy Award-winning film actor died at the age of 82.

Gerry Halliwell-Ginger Spice, leaves the chart-topping Spice Girls band.

Bill Clinton became the centre of a sex scandal. His affair with Monica Lewinsky became public knowledge after a friend of Lewinsky secretly recorded conversations of sexual encounters in the White House.

On the box...
Coronation Street fans lost sight of the difference between reality and fiction when one of the characters, Deirdre Rachid, was imprisoned for something she didn't do. Newspapers ran 'Free the Weatherfield One' campaigns.

In vogue...
David Beckham started a new trend for men by wearing a sarong in public - and suddenly lads everywhere were

Clipping One:
Tidings Issue No.1 (1998)

Carer's Corner

Sure it's tough when seeing your surgeon to be given the news:

"You'll have to wear a bag permanently". As colostomists we need no reminding of the traumatic thoughts racing through our mind when that statement is heard. The trouble is that for us humans, selfish thoughts are a natural reaction. But what about wives and partners? What must they have thought? Listening to this feedback at a coffee morning which I had the pleasure of holding for local carers, (not the colostomists themselves), was a revelation. They were able to speak quite openly about their emotions.

Ken Foss

following suit. He also got engaged to Posh Spice, Victoria.

Clipping Two:

Tidings Issue No.1 (1998)

Well known stoma care nurse retires

After 40 years in the NHS and 17 years as Stoma Care Sister at Heartland Hospital, Birmingham, Mary Cotterill has retired. During her time at Heartland, Mary and her colleague Sister Pat Connor saw the founding and building of the first purpose built Stoma Care Unit, the Ruth Astler Centre. Named after a stoma patient who left the hospital a sufficient bequest to fund the centre.

Oldest person in space...

John Glenn, 77, U.S. senator and legendary astronaut, became the oldest person to fly in space, 36 years after he became the first American to orbit Earth.

Sporting history...

18 year old Michael Owen became the youngest footballer to play for England in this century. He scored a wonderful goal against Argentina in the 1998 World Cup Finals in France then shocked the Germans with a hat-trick in Munich in 2001.

Medical wonder...

Viagra promised a cure for sexual impotence which affects one man in ten. The little blue pills promised to usher in a new age of sexual liberation for the over 40s, and such was the excitement that one couple were even invited to try the drug 'live' on This Morning with Richard and Judy. It is not recorded whether the presence of the celebrity couple accentuated or counteracted the effects of the drug. But a thriving black market in the little blue pills sprang up soon after.

At the Cinema...

James Cameron, Hollywood director, proclaimed himself “king of the world” as his blockbuster Titanic picked up awards in 11 categories at the 70th annual Academy Awards ceremony on March 23. Captivating millions of fans with its real-life premise, its powerfully romantic storyline, and the popularity of its young stars, Leonardo DiCaprio and Kate Winslet, the movie quickly replaced Star Wars as the top-grossing film of all time.

Other films showing were-
There’s Something About Mary
Boogie Nights
Saving Private Ryan

In the Charts...

A year of short-lived No.1s.
From All Saints to Aqua.

On TV...

The Royle Family
Goodness Gracious Me
South Park

Must have toys...

Beanie Babies, Yo-Yos and the Furby

Clipping Three:

Tidings Issue No.1 (1998)

On a Sporting note

Imagine my surprise on being accepted into the Senior Citizens section of the local golf club, to find that two other colostomists were already members, we’re not such a special breed after all.
In addition, one of the fellows has a false leg and what a super chap he is. To cap it all, I then joined our indoor Bowls Club and promptly discovered that I am in similar company here as well!
There are many sports apart from golf and bowls: tennis, swimming, cricket, archery to name but a few. its good to get out into the open air, so if you’ve ever thought about having a go at something... go ahead and do it!

Now try the quiz...▶

Tidings – Taking you back to 1998...

Tidings Anniversary 1998 Trivia Quiz

1. Which football team won the 1998 World Cup?

a) Brazil
b) France
c) Germany

2. Which hurricane killed more than 10,000 people in central America in 1998?

a) Mitch
b) Rosie
c) Andrew

3. Which rock group performed the title song for 1998 hit TV series The Royle Family?

a) Oasis
b) The Stone Roses
c) Slade

4. What happened to Coronation Street's Deirdre Rachid in 1998?

a) She was deported
b) She was imprisoned
c) She was murdered

5. Which blue-eyed star died in 1998?

a) Laurence Olivier
b) Elvis Presley
c) Frank Sinatra

6. Who played Mary in the 1998 film There's Something About Mary?

a) Cameron Diaz
b) Sigourney Weaver
c) Kate Winslet

7. A new currency was agreed for Europe in 1998. What was it called?

a) Euro
b) Ecu
c) Groat

8. Who became the youngest footballer of the 20th century to play for England in 1998?

a) David Beckham
b) Michael Owen
c) Wes Campbell

9. Which country did 1998 Eurovision winner Dana International represent?

a) Ireland
b) Israel
c) Italy

10. What was the name of Mark Wahlberg's character in the 1998 film Boogie Nights?

a) Randolph Thrust
b) Dirk Diggler
c) Jack Horner

Answers below:-

1=b, 2=a, 3=a, 4=b, 5=c, 6=a, 7=a, 8=b, 9=b, 10=b

Tidings Magazine Anniversary issue 10 YEARS 1998-2008

Clipping Four:
Tidings Issue No.1 (1998)

A letter to BCA

I am writing to thank you very much for the advice and support offered so unselfishly in respect of my Dad. Although very sadly the outcome was not what we all hoped for, we still very much appreciated the time you gave to us all as a family. No words can express our gratitude to you.
We only wish we could have contacted you sooner.
Time is the most precious gift you can bestow and you gave us yours freely. People like you are the heroes in life but do not receive the praise they so richly deserve. We were extremely touched by your presence at the crematorium, another measure of the depth of your kindness, my Dad would have appreciated that. You came into our lives at a time of despair, yet there was no awkwardness, only empathy. The world would be a better place if everyone in it demonstrated even a fraction of your kindness shown. We all hope that you continue in good health and live a full and happy life. Thank you again. We will always think fondly of you.

Kindest regards,
Janice

colostomy association

Anniversary Raffle

WIN the fantastic NEW Vauxhall Agila Club with a ticket price of just £1.00

Simply enter the Raffle...and you could be our WINNER
Raffle Tickets are a bargain at £1.00 each

Two books of tickets are enclosed with this issue of Tidings
further tickets are available on request from Head Office

The Vauxhall Agila was supplied by
Sonning Common Garage Ltd Sonning Common Reading RG4 9RN
and the draw will take place at
their showroom on 15th November 2008 at 1.00pm

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Tidings Magazine Anniversary issue 10 YEARS 1998-2008

Update - Department of Health and Scottish Government Consultations

The latest Department of Health (DoH) Consultation documents were published on the DoH website on Monday 9th June. As we close for press (11th June), indications are that the proposals contained in the Consultation are a great improvement on the previous documents. This is a clear indication that the feedback to the previous Consultations, and the follow up meetings that took place with the Manufacturers, Nurse Associations and Patient Groups, has been heard by the DoH and appropriate actions taken.

Whereas the previous Consultation suggested that savings of £25m would need to be made in the reimbursements made to companies for supplying stoma products, this document now requires savings of £5m in this area. Early indications from the Manufacturers are that these proposals are workable and should not have a significant impact on the range of products that they will be able to offer.

The Consultation can be found on the Live Consultations page of the Department of Health website and is titled ‘Proposed new arrangements under Part IX of the Drug Tariff for the provision of stoma and urology appliances – and related services – in Primary Care’. The closing date for responses is 9th September 2008 and we will be submitting a response on behalf of the Colostomy Association.

We will provide further comment and analysis of the proposals on our website in due course.

Scotland

A number of ideas have been suggested by the Scottish Government, with regard to the supply of stoma equipment, but before any of these can be put in place a consultation process will need to be followed.

Representatives from the three main Patient Association for Ostomates (Colostomy Association, Ileostomy Association and Urostomy Association), are planning to meet with Scottish Health representatives in August to try to clarify the situation and seek assurances on the service provision to patients.

If any of our Scottish members are noticing any changes in the service, or choice of product, that they receive, we would be interested to hear from you. Please write to Ray Goddard, Office Manager, Colostomy Association, 2 London Court, East Street, Reading, Berkshire, RG1 4QL or e-mail us at cass@colostomyassociation.org.uk.

colostomy association

Christmas Cards Reader Offer...

The husband of one of our volunteers has very kindly painted two watercolours exclusively for us to use as illustrations for our Christmas cards and I am sure that you will agree that they capture the Christmas feeling superbly.

We are pleased to be able to offer these cards for sale to Tidings readers.

Boxed set of 8 Christmas cards (two different designs as shown above) with matching envelopes available at £3 per box inclusive of postage and packaging.

How to order: If you would like to order a box/boxes of cards, please complete and return the order form to ‘Christmas Cards’, Colostomy Association, 2 London Court, East Street, Reading, Berkshire RG1 4QL, or telephone the office on 0118 939 1537.

Order Form: Christmas Cards Offer...

Please forward ____________ box/boxes of Christmas cards at £3.00 per box

I enclose a cheque for £ ___________ made payable to the Colostomy Association inclusive of postage and packaging

Name: ____________________

Address: ____________________

____________________ Postcode: __________

My stoma comes of age

Janice is a volunteer with the Colostomy Association. She attends Open Days and is a member of the “Out of Hours” helpline team.

I came into being on January 30th 1990 as Janice had bowel cancer. She woke to find me on her tummy - a “bag for life”. She will tell you it took a while to get used to me. Most of the time I behave. Sometimes I can play her up, not often though, but I like to make myself heard! Janice soon got on with her life, returning to full time work and family life – being mum to Richard and Gemma.

In 1996 we abseiled ninety-five feet off Haytor on Dartmoor and squeezed through narrow channels whilst caving. We came through divorce, moving house and have been there when close friends and family have passed away. Janice remarried and when choosing her wedding dress had to think about me to make sure I didn’t show.

We’ve been at Richard’s wedding and Janice is now grandma to Harry who has just had his first birthday. We were proud to be at Gemma’s graduation at Reading University.

Janice meeting Tom Cruise on her fiftieth birthday.

We’ve seen a few celebrities in the last eighteen years: Rod Stewart, Status Quo, Lenny Henry, Kathryn Jenkins, Blondie and Mike Reid. Janice has had a kiss from Paul Young. We’ve seen David Essex so many times I’ve lost count. Once I played up at one of his concerts, maybe I thought I’d heard it all before! Anyway Janice had to go to the loo and got back to her seat just as the concert was about to start. However, she did get to speak to David Essex and has his autograph. We’ve even seen and spoken to Hollywood star, Mickey Rooney. The biggest buzz for Janice was when on her 50th birthday trip to London she had her picture taken with Tom Cruise. He was in Leicester Square for the premier of Mission Impossible 3.

We’ve been on lots of holidays; I have no problem flying. We’ve had fun in the Canaries, taken afternoon tea at Reid’s Palace in Madeira, been on the Glacier Express in Switzerland and climbed the 550 steps to the top of Cologne Cathedral.

Janice is a volunteer with the Colostomy Association. She attends Open Days and is a member of the “Out of Hours” helpline team.

All this would not have been possible for Janice if I hadn’t stuck with her. Instead of a party to celebrate we just reflected on the last eighteen years and decided to send a cheque for £18 to the Colostomy Association to keep up the good work. Here’s to the next eighteen years when hopefully we’ll see another milestone – retirement!

Here's what's happening...at Head Office

Office Move...

At the end of April the Colostomy Association Head Office moved premises from Station Road, Reading to London Court, Reading. Having been based at Station Road for eighteen years there was a lot of opportunity for a 'spring clean' of all of our cupboards, drawers and storage spaces. This meant that we could start afresh in our new offices and set up everything in just the way that we wanted.

A lot of hard work was involved in the move, not least by the removal company who had to move all of our furniture, boxes etc out of Station Road via a small lift or four flights of stairs. London Court does have car parking facilities but problems were encountered when the lorry attempted to back up quite a steep entrance way to reach the car park. This was eventually overcome and the final items of furniture were delivered at about 6.30 p.m. on Friday evening.

Look we've moved...
our new Office Address

Colostomy Association
2 London Court
East Street
Reading
Berkshire RG1 4QL

Helpline: 0800 328 4257

E-mail:
cass@colostomyassociation.co.uk

Website:
www.colostomyassociation.co.uk

During July we will be launching of our new and improved website - www.colostomyassociation.org.uk

Visual of the proposed site

We are very pleased to be able to announce the launch of our new improved website which will take place during July.

Some of the new features include:-

- The facility to download/print copies of our literature and fact sheets
- The ability to make donations on-line
- A Resource/Knowledge Centre with access to a wide range of helpful information.

Please visit the website and let us know what you think.

Our new look Factsheets - will provide colostomates with helpful information and contact details for products and services - these will be available for download shortly

In the News...

CliniMed and SecuriCare Awards

CliniMed Ltd and SecuriCare Medical took part in the 2008 Pharmaceutical Fields Awards – the premier awards event in the UK pharmaceutical calendar that recognises excellence in pharmaceutical sales and marketing in a variety of categories designed to highlight achievements and innovation, together with patient care initiatives.

The 2008 event saw a total of five hundred entrants within thirteen categories and of these, 220 were short listed to attend an assessment day and to present in front of a panel of judges.

CliniMed and SecuriCare Medical were chosen as finalists in the following categories

Nurse Advisor – Pam White
Nurse Manager – Fiona Baines
Patient Care Initiatives – Gill Reay Jones, Alison Benn and Frances Chalmers
Innovations – Frances Chalmers

Pam White was the outright winner of the Nurse Advisor Award which was presented at the Royal Lancaster Hotel in London on 13th March 2008.

We send our congratulations to Pam and all the other finalists from CliniMed and SecuriCare for their superb achievements.

Outlook Support Group...
North Staffs Ostomy Support Group Outlook's Annual Exhibition and Patient Open day takes place on Saturday 25th October 2008

North Staffs Ostomy Support Group Outlook's Annual Exhibition and Patient Open day at St Wulstans Community Centre. Church Lane Wolstanton. Newcastle Staffs ST5 0EF (for the Sat Nav's) on Saturday 25th October 11 am to 3 pm. Tea, Coffee, light refreshments.

New products and services with all the leading manufacturers in attendance plus representatives from the University Hospital of North Staffs Bowel Care Team. An interesting day for all Ostomists, 5 minutes outside Newcastle town on the edge of Wolstanton marsh, next to the village pub, 2 minutes away from Wolstanton retail park and 5 minutes from the Festival Retail park and Waterworld. All welcome.

Contact Ernie Hulme on 01782 324441 for details.

Adrian March MA PhD resigns as a Trustee and becomes a consultant to the Colostomy Association

In view of continuing communications difficulties, which have made it impossible for him to discharge fully his legal obligations, Adrian March has resigned as a Trustee, and taken up the position of Consultant to the Colostomy Association. Adrian has since August 2006 lived in Provence, in the south of France, and wishes it to be understood that the change is intended to facilitate his contribution to C A, rather than diminish it.

Adrian has had a colostomy for ten years, as a consequence of ano-rectal cancer, was a Regional Great Comebacks Award winner in 2001, and was one of the founding Trustees of the Colostomy Association. Professionally a consultant in advanced engineering research, Adrian has for many years, as a tutor of the Amateur Swimming Association, taught and trained teachers in swimming, diving, and aqua aerobics, and as a tutor for the National Coaching Foundation lectured to sports coaches on a variety of subjects, including anatomy, physiology, and the technique of coaching young children. He has made good use of this experience in the Technical Notes which he has written on a wide range of subjects relating to exercise, fitness, and sport after abdominal surgery, and the problems with which a colostomate may be faced in moving to France. He will also be speaking at the National Conference in September.

Adrian manages two websites:- www.stomadata.com (StomaData) and www.stoma.fr (Stoma), both of which have the Colostomy Association leaflets and eleven of Adrian's Technical Notes available for download. The difference is that whereas StomaData also has a small "Cookery Corner" with some healthy eating recipes, Stoma omits the recipes but is being developed into a bilingual site, on which all the information will ultimately be available in both English and French. It is planned for StomaData to include a Young Colostomates page and readers of Tidings are invited to suggest an appropriate name for it, as well as the features it could have. Take a look at both!

Lake District Clinics

For those Ostomates in the Lakes area, Stoma Care Clinics have been set up by the North Lancashire NHS, in various locations.

Grange over Sands:
Grange Clinic, Hampstell Road
2nd Wednesday of each month
10am – 12 noon

Lancaster: Ryelands House
Every Tuesday 10am – 12noon

Kendal: Westmorland General Hospital, Burton Road
Every Monday 10am – 12 noon

Windermere: Windermere Health Centre, Goodly Dale
1st Wednesday of each month
10am – 12 noon

Please contact Moira Robinson (SCN) 01524 848357 to confirm opening times.

Dear Nurse...

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

Q: My mum is eighty-one and had a colostomy operation in May 2007. It has been functioning well and she is due to have a barium test to see if a reversal is possible.

On three occasions she has passed stools via her anus. The first time, about seventy days after the operation, was obviously residue. It has now happened again on two occasions in January. I called the consultant's nurse and have been told not to worry and that this is a very good sign. I simply cannot understand how this can be possible as it is not mucus or residue but healthy looking faeces.

Any information you can give me would be greatly appreciated.

A: This can happen even such a long time after surgery, especially if the bowel was not prepared before the original operation as debris will be left in the bowel. As long as your mum is well in herself the barium examination will identify if she is able to have the reversal. Occasionally it may be necessary to use glycerine suppositories to remove the debris from the redundant bowel, especially if there is a feeling of fullness or discomfort and this can be arranged following a visit to your GP.

Q: My mother had a bag fitted over twelve months ago after having most of her bowel removed. She is seventy five now and is okay with the bag during the day but at night when she is in bed it leaks and this causes her distress. I know that before she goes to bed she changes it and I also know she watches what she eats. I'm just wondering if there are any bigger bags that are available just for bedtime.

A: I am not sure which pouches your mum is currently using but there are many different types and sizes available. It may be worth asking to see your own Stoma Care Nurse who can assess the stoma and provide your mum with samples of different pouches to try. The problem may also be due to the consistency or amount of the output and again a review by your Stoma Care Specialist Nurse would help with assessment and treatment of this if it is the cause of the nocturnal leaks.

Q: I have a friend who is only twenty-four and has been told due to ulcerative colitis she has to have a stoma. She is very worried that because of this she might not be able to have children. Is this the case?

A: This is obviously a very worrying time for your friend and she really needs to speak to her surgeon and her Specialist Stoma Care Nurse to discuss all her options and the risks associated with them, including the risk of infertility. She can also get a lot of information from the patient support groups and it may be helpful to contact both the Ileostomy Association on 0800 0184724 or www.the-ia.org.uk and the National Association of Crohns and Colitis on 0845 1302233 or www.nacc.org.uk.

Q: I am twenty-nine years old, have Crohn's disease and in April 2007 I had an end colostomy. The operation was very successful and for the rest of last year I felt like a normal healthy lady but I have always been sensitive to the stoma bags and had red sore skin. (Three years ago I was put on Methotrexate for my Crohn's which made my skin photo sensitive.)

Last December my stoma changed drastically in shape and the skin grew over the top and the stoma seemed to go inside. My surgeon has prescribed Hydrocortisone 2.5% cream to use on the stoma and the sore skin every time I change my bag. It has helped to a certain degree as I can now see some pink healthy stoma.

However, I would like to try and find a cure to this sensitivity and not be reliant on a steroid cream indefinitely as my colostomy is a permanent one. My surgeon has said that unless they can sort out my skin they may have to re-site my stoma to my left side, but I can't see how this will help as surely I will develop a reaction on the other side.

I would be very grateful if you could help.

A: As your surgeon has said this appears to be a skin problem rather than a stoma problem and therefore, even with re-siting of the stoma the problem with the skin may continue. It may be worth asking for a referral to a Dermatologist who may be able to help with this problem. Either your surgeon or your GP should be able to do this for you.

Q: How does open surgery to remove part of the bowel affect those who suffer from irritable bowel syndrome?

I'm seventy years old and for over forty years I've put up with spasms, bloated abdomen, diarrhoea, tiredness and depression. Last January I had an operation to remove a suspicious flat polyp which turned out to be malignant (Dukes A) but no chemotherapy was thought necessary. After four days I suffered a leak and was returned to theatre for emergency surgery followed by nine to ten days in intensive care with lung and pelvic infections. The pelvic infection needed opening up and draining. This left me with a wound which needed treatment for ten months by

Dear Nurse...

district nurses. It finally healed last November but has left me with an incisional hernia.

Now over a year later the subject of a reversal operation has been discussed. I have agreed to have my hernia repaired but I'm putting on hold any plans to go ahead with a reversal, owing to a very short rectal stump and IBS. I am taking the view that a reversal operation would probably lead to the problem of urgency and at worst incontinence. If that happened it might be necessary for further operations to return me back to where I am now.

Yes of course there are exercises that can improve control but after careful thought I've considered I'm marginally better off avoiding any more open surgery at the present time. I don't like having colostomy bags but that is surely better than incontinence pads.

Yes I have the option of changing my mind on future surgery but I live alone and at the moment my decision is no. I would very much like your opinion and to hear from other IBS sufferers who may have their own experiences to tell especially on the rather daunting decision regarding reversal operations.

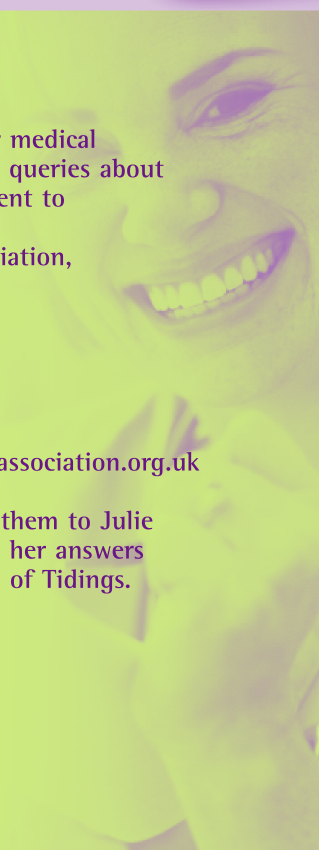
A: I am unsure how much bowel was removed during your first surgical operations and therefore am unable to comment on the chances of frequency, urgency and the need to wear pads following this. Many patients have reversal of their stomas and do not suffer these problems but obviously everyone is an individual and many factors need to be considered. I would suggest you talk in detail to your surgeon and your Stoma Care Nurse both of whom can explain the potential risks for bowel problems afterwards and can give you more individualised information regarding your previous surgery and the implications for a reversal for you. They may also be able to arrange for you to speak to a patient who has undergone a reversal of their stoma previously and you can get the patients view on the procedure.

To get more information regarding IBS you could ask if your local hospital has a Specialist Inflammatory Bowel Nurse who could help or ask your GP for any relevant information leaflets on this condition.

Q: I have just had a Colostomy one month ago. I am a vegetarian and I am suffering badly with trapped wind. It sometimes gets so bad that I start vomiting. I have asked my stoma nurse but all I get is 'your diet' which does not help me at all. I wonder if anybody has some useful tips to help me out. I am getting scared that I will not want to eat due to this and I know I cannot think like this so please help me!!

A: I am sorry to hear you are having problems with your diet and 'wind' following your surgery. You say you had your surgery a month ago so it is still very early days yet and you may find that as time passes the problems settle. However certain foods can increase the potential for 'wind' especially as you are a vegetarian. Some patients find that using things such as peppermint (tea, mints or cordial), fennel (tea, mints, tablets or the vegetable) or charcoal (tablets or biscuits) can help to reduce the amount and severity of the wind. Otherwise it is correct that you need to assess your diet and see if there are any particular foods which cause the wind to increase. You can then avoid these foods in the short term and gradually re-introduce them as time passes. I hope this helps.

Dear Nurse...



Please send your medical questions or any queries about stoma management to

Colostomy Association,
2 London Court
East Street
Reading
RG1 4QL

or e-mail
cass@colostomyassociation.org.uk

We will forward them to Julie Rust and publish her answers in the next issue of Tidings.

What is a prolapsed stoma?

A prolapse of the stoma occurs when the bowel protrudes through the stomal opening in the skin to a greater extent than was anticipated. The severity of the prolapse can vary from a small 2-3 cms prolapse to a large 10cms plus prolapse. Any prolapse is frightening and distressing for the patient and should be handled sensitively by a trained Health Care Professional. The patient should be referred to the Consultant Surgeon or the Specialist Stoma Care Nurse for careful assessment to ensure successful management of the condition.

Contributing Factors

A prolapse can occur in any stoma type but is more common in loop stomas, especially loop transverse colostomies (McCahon; 1999). The causes of a prolapse are many but include an oversized hole made in the abdominal wall at surgery (McErlain et al; 2004), increased abdominal pressure due to tumour, pregnancy or chronic coughing (McErlain et al; 2004), excessive exertion, including heavy lifting (McCahon; 1999) and obesity (McErlain et al; 2004).

Management of the Prolapse

Management of the prolapse can be conservative or surgical but all patients must be given support and reassurance during this frightening time. The psychological effects of having a large piece of bowel protruding through the abdominal wall, often being visible under clothing, can be great and fear of further problems can be a considerable factor. For any degree of prolapse the main consideration is psychological support. The patient should be given a full explanation about what a prolapse is, what may have caused it and what to look out for with regard to change in the condition of the stoma. They should be advised to be careful when handling the stoma so as not to cause any degree of trauma to the bowel and to note any change in colour, size or activity, which needs to be reported to the Specialist Stoma Care Team. If the prolapse is small some degree of adjustment with regard to appliance type may be all that is necessary to successfully manage the problem.

Many ostomy product manufacturers now make specialist pouches to help in the management of both herniated and prolapsed stomas. Referral to the Specialist Stoma Care Team will provide the patient with advice regarding the use of an appropriate appliance, which needs to be large enough to contain the prolapsed bowel and the output easily. The template should also be checked to ensure that it fits correctly around the stoma without causing undue pressure leading to trauma (McCahon; 1999).

Courtesy of Salts Healthcare

The use of a light weight abdominal support can also be beneficial as long as it is assessed prior to use by a Health Care Professional to prevent trauma to the prolapsed bowel (Myers; 1996).

For prolapses which are too large to manage conservatively, or for a prolapse which becomes discoloured surgical review is necessary for assessment regarding refashioning or even reversal if this is appropriate (McErlain et al; 2004). Surgical intervention is undertaken following review by the Consultant Surgeon and will involve removal of the prolapsed section of bowel and refashioning of another stoma, possibly being sited in another area of the abdomen.

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Myers C. (1996) Appliance leakage. In Myers C (Ed) Stoma Care Nursing: A Patient-Centred Approach London, Arnold

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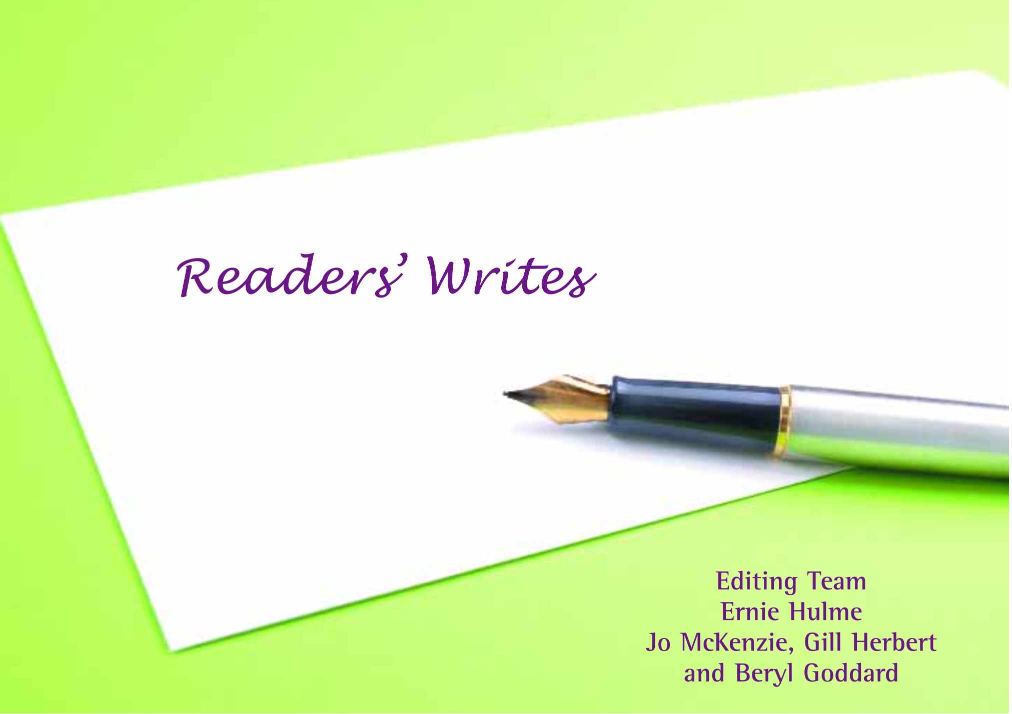


Readers' Writes

Editing Team
Ernie Hulme
Jo McKenzie, Gill Herbert
and Beryl Goddard

Dear Editor

I am a new reader of your magazine, Tidings, and have received three issues. My permanent colostomy was formed in June 2006 due to rectal cancer. I found it very hard to come to terms with the new way my body performed and felt dirty and abnormal.

Since reading the experiences of other colostomates through your magazine and of the varied ages, I have felt different. Before I felt that I was the only one dealing with this problem and rather alone. Now I have so much more confidence.

Thank you for your wonderful magazine which also contains so much useful information. I look forward to receiving further issues.

Yours sincerely
S.J. (Mrs)

Dear Editor

I enjoy reading Tidings as a lot of it relates to my own problems. Due to bowel cancer I now have a stoma which cannot be reversed. I've had it for nearly three years and have had my problems with it due to extensive chemo and radiotherapy.

The radiotherapy has left me with sickness and diarrhoea which I have now had for nearly eighteen months and I do sometimes get a leaking bag. However, my reason for writing is to say that this has not stopped me from going New Zealand for six weeks – something I thought I would never achieve. We left on 9th December 2007 and came back on 23rd January 2008. It was three days travelling on both outward and return journeys, but even the flights were not too bad. We stopped in Dubai overnight on the way there and back and the flight staff were very kind and helpful.

So life still goes on, even after a colostomy. We've been back home now for three weeks and we certainly hope to go again in two or three years time.

Yours sincerely
P.A.F. (Mrs)

Dear Editor

Thank you so much for the helpful articles published in Tidings over the last year, particularly those relating to travelling as an ostomate, coping with a parastomal hernia and reversals. I have had my colostomy less than a year and am now looking forward to a reversal.

I have recently returned from a fabulous holiday to New Zealand, during which time I had no problems whatsoever with my colostomy. I had to pay extra for a travel insurance policy that included my medical conditions (colostomy and others), but it was worth it for peace of mind.

During the long flights I had no trouble at all with anything: I had all my spares and associated paraphernalia, including baby wet wipes (a god-send!) in a make-up pouch that I could easily carry every time I went to the toilet, so I could change my bag as required. I had more supplies in my suitcase and, since my mother was travelling with me, I put some supplies in her suitcase, too. I took a few drainable bags in case of an upset tummy but didn't need them. In fact, managing my colostomy while flying was no more difficult than managing it at home!

Throughout the tour I carried my make-up pouch of spares in my day-bag and I don't think anyone else realised that I was in any way different from the rest of the group. I don't normally use the disabled toilets when I am out and about and need to change my bag, so I didn't in New Zealand.

The only problem I had during my whole holiday was nothing to do with my colostomy: the zip on my trousers broke one morning just after we got on the bus for the day! Fortunately, my T-shirt was long enough to preserve my modesty.

The article in Tidings last year on travelling as a colostomate was very helpful as was the member of staff I spoke to when I rang CA to request a travel certificate. I have also had excellent advice from an internet-based support group, Ostomyland. Armed with so much advice and information, it would have been difficult not to enjoy myself! I had a wonderful time and I hope that my story will encourage other colostomates who are nervous of travelling to give it a try.

Yours sincerely,
M.B. (Mrs)

I am sure other new ostomates who are have concerns about travelling abroad will be encouraged by your letter. We do hear of some people with a temporary stoma who put their life "on hold". Your story shows that it isn't necessary to wait until you have had a reversal operation to get on with all the things you have planned in your life. Ed.

Dear Editor

I have for some years worn a stoma bag and find that each bag needs trimming with scissors before it is fitted to ensure a close fit. This is partly because the scar tissue seems to change shape a little depending on the last meal.

On two occasions in the last three years I have travelled by air and the employees of British Airways and their agents in Italy and Turkey have sought to confiscate my short blunt-ended scissors which they say cannot be included in cabin luggage. Each time I have explained I may need to change a bag during the flight. Also if the scissors are carried in the hold of the aeroplane and the luggage is delayed or lost I will be in considerable difficulty.

Both times I have carried a letter from my GP explaining why it is necessary for me to carry a pair of scissors with me. However, after twenty minutes argument, and on one occasion a phone call from Italy to London, I have been allowed to take scissors into the cabin. When returning from Turkey it was a condition that they were handed to the captain who I was assured would hand them to me when required. In the event he refused to pass them to a crew member for my use because they were in his custody in a plastic bag.

I have a copy of a leaflet issued by BAA listing items allowed as hand luggage, which included medicines...essential for your trip, for example diabetic kit. However, despite six months correspondence before my trip to Turkey there is no recognition of the problems of those who wear a stoma bag.

Before taking the problem any further I would like to know whether any of your readers have had similar difficulties. In addition to any correspondence in your magazine which may arise from this letter I should be pleased to receive letters detailing other people's experience. I think it is time there was an international protocol defining who may carry scissors as hand luggage and details of permissible scissors.

Yours faithfully

Mr P Green
12 The Platt
Sutton Valence
Maidstone
Kent
ME17 3BQ

Dear All

Your magazine has been a wonderful lifeline since unexpectedly having a stoma after surgery for colon cancer 18 months ago. It has helped me tremendously just knowing there are so many other colostomates 'out there'. I have found the features helpful and reassuring and even the adverts have helped me to know the wide choice of various products available.

I have been fortunate in that I have had no trouble (touch wood) in coping with my colostomy. In fact during recent chemotherapy treatment, when the worst side effect was chronic diarrhoea, having a colostomy to me was a blessing in disguise. The drainable bag was a godsend!

Yours Faithfully

S. W.

Dear Friends

I do look forward to receiving Tidings. My daughter arranged it for me after coming out of hospital after being in intensive care for nearly three months, after an emergency operation for a flare up of Diverticulitus and peritonitis. It was a difficult time for my family after being told I would not survive the operation, but their love and devotion pulled me through. I am nearly back to full strength. Tidings makes me realise how fortunate I have been when I read what other people have gone through. Your team do a wonderful job.

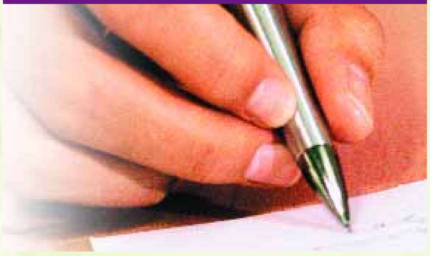
Keep up the good work.

Yours sincerely
J. M. B.

From Ed...

Dear All...

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



Never look back... life is for living

On 28th March 2008, after 40 years of nursing, I decided to retire from the N.H.S. The last five years in particular have been an achievement, because in 2002 I was diagnosed with bowel cancer.

My story began in May 2002. I decided to go on a 'detox diet'. After a couple of days I thought I was going to disappear as a result of the very efficient bowel emptying process. I very quickly stopped the 'diet' but even after a few weeks my bowel habit was not back to normal. I made an appointment with my G.P. and explained to her what had happened and what I was feeling. The appearance of the stool was flat, and it felt as though I was pushing it over something.

My GP didn't hesitate (although reassuring me at the same time) to fast track me to the local hospital where I quickly had an appointment with the gastroenterologist. (I must confess that concern had taken over and I requested a private consultation). I was seen within a few days and a colonoscopy was recommended for the following day. Timing is everything: we were to go away on holiday for a week. Had it just been the two of us, my husband and myself, we would not have gone, but my sister in law was over from New Zealand and my father in law was also coming along. How could I cancel? What could I tell them? I didn't at that time have a diagnosis. What a long week it was.

On my return I had the colonoscopy and the news was not what I wanted to hear. There was a large tumour in the bowel and there was evidence of lymph involvement. How long had it been there? 1 year? 2 years? How do you know?

Waiting for the phone call for the C.T. and the MRI scans again seemed like an eternity. My husband had packed a bag and driven us both up to the Lakes because it all felt very claustrophobic. It was as though we needed some space to think and to try to absorb the news.

After the scan the surgeon and the oncologist decided that the best cause of action for me was to have surgery, so on August bank holiday Monday 2002 I was admitted into hospital. I had seen the colorectal nurses and the procedure had been explained to me. X marked the spot where the colostomy would be. It was all a bit of a blur.

The required recovery time went by. I remember sitting doing a lot of nothing in the garden during the months of September and October and getting used to my new companion. After all it was here to stay.

The courses of chemotherapy and radiotherapy were organised. It would take six weeks in all and would finally get rid of what was not needed. That treatment took me up to the New Year of 2003.

There was another holiday looming. This time it was the skiing season. I certainly was not feeling up to it. As each day went by with a lot of rest, sleep and being looked after by my husband I started to recover so by the middle of February we went away. I did not ski that year but the weather did me the world of good. I was able to walk every day. On my return I decided that I would return to work and on the 1 April 2003 I took up where I left off just six months after it all began.

I have not looked back. Life is for living. I walk every day and belong to a rambling club. In fact my colostomy does not stop me doing anything.

Julia Lipman

Marketplace

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

Open Days held by Nursing Professionals

Colorectal and stoma care nurses from the following hospitals are holding Open Days during July, September and October

Stirling Royal Infirmary
Date: 5th July 2008
Time: 11am–12noon
Venue: Conference Centre
Stirling Royal Infirmary, Stirling.

Princess of Wales Hospital
Bridgend
Date: 20th September 2008
Time: 10.30am–12.30pm
Venue: Oasis Restaurant
Princess of Wales Hospital.

Kettering General Hospital
Date: 2nd October 2008
Time: 1pm – 4pm
Venue: Recreation Hall
Kettering General Hospital.

Stoma Care Open Days organised by nurses working within the NHS, where several manufacturers and suppliers are represented, will be included on this page free of charge.

For a complete list of forthcoming Open Days visit our website www.colostomyassociation.org.uk and click on events.

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

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

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

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

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Visit our website at www.whiterosecollection.com

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www.imedicare.eu

Available on NHS Prescription for men who have had radical pelvic surgery (including Colostomates) or over the counter:
SOMACorrect Xtra:
Order code - 15111
SOMAerect Response II XL:
Order code - 15888

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Linda Butler
(a fellow Ostomate).

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Tidings

Dedicated to Colostomates and their Carers

www.colostomyassociation.co.uk

Bristol Ostomates’ Self Support Group

The group was formed in 1991 when some stoma care nurses got together and were realising that there was a shortfall in support for new patients who were faced with the uncertainty of having a stoma formed and what that would entail.

The nurses set on a mission to deal with this and sent out invitations to all patients in their records. ConvaTec kindly sponsored our inaugural meeting at one of the local hospitals. A large number turned up to this meeting to discuss the need for a support group. It soon became clear that this was a very popular idea. A core group of patients offered to form a committee to run this support group which was called BOSS, Bristol Ostomates Self Support Group.

We now have roughly 100 members whose families, friends and carers are also welcome. They come from all over the South West and meet four times a year in Bristol. The meetings are held on a Saturday afternoon, and a speaker is invited to talk. We start the meetings by introducing our new members and then a speaker will talk on a variety of different subjects. This is followed by refreshments and a good chance for people to mix and chat to one another. It is a very friendly group and no one needs to feel alone. The most popular meeting is of course our December Christmas party when we have festive refreshments and a special visitor in red!

Our annual trip to the theatre is very popular, and this year forty of us are looking forward to seeing Aspects of Love.

A stoma care nurse attends all our meetings. Our members can talk to her in confidence if they are having any problems. She will also do home visits to our members.

BOSS have very good connections with the local hospitals and a core of us have been trained to act as ‘listener/visitors’. The stoma care nurse will contact the co-ordinator of this group and a listener/visitor will be asked to phone and/or visit the patient. This has resulted in people who may be feeling at a loss prior to surgery or very alone following surgery becoming more confident having been able to discuss their uncertainties and fears.

Any member of BOSS going into hospital will not be forgotten.
They will be contacted by our welfare co-ordinator who will ensure that they have what they need and keep in contact with them till they are home again.

We have a newsletter which goes out twice a year with useful addresses, ideas and news about our members, plus an article or two. This also goes to the hospitals and is another good way to spread the word about our support group.

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

Tidings
Dedicated to Colostomates and their Carers

You can visit our website at:
www.ostomyweb.org.uk

Contacts details:
Maurice Cox 01179 358949
Joyce Roderick 01179 558236

News of local stoma support groups...

The Optomists in Cornwall now meet in Carnon Downs Village Hall on the A39 between Truro and Falmouth.
Dates of next meetings :
5th August 2008
2nd September 2008
7th October 2008
For more details contact Sue Hatton 01326 340058

Jersey Ostomy Society (J.O.S.) is a new support group. They hold quarterly meetings, the next one being 18th September 2008. **For more information please contact Connie Gardner 01534 759569.**

The Guernsey Ostomates meet at St Martins Community Centre at 7.30pm in the Moulin Huet room. Next meetings:
30th July 2008
27th August 2008
24th September 2008
29th October 2008
Contact Simon De La Mare for more details 01481 254081. All Ostomates and carers are welcome.

S.C.A.R. (Stoma Care And Recovery) are a support group in the Kilmarnock area which meets on the first Tuesday of the month.
Dates of next meetings:
5th Aug 2008.
2nd Sept 2008
7th Oct 2008.
For details of the times of the meeting and the venue contact:
Maggie 078177 36147
Rhona 01294 557478

Get your Support Group Published - If you contact us before 22nd August 2008 we will publish the date and venue of your next Stoma Support Group meeting.

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

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


Lift Plus
Non Sting

Fundraising...we need your help

Thanks to Ruth Gardner and friends...
We received a cheque for £260 from Ruth Gardner, who, along with a few friends, held a coffee morning and donated the proceeds to the Colostomy Association. Ruth had a colostomy due to bowel cancer ten years ago and is eternally grateful for the support received.

Thanks to the dressmaking friends of Catherine Thompson...who raised £85 through material donated by Catherine. Joan Etherington wrote in to us and said 'Catherine has gained a lot of help and information from your Association and we hope that this small gesture will continue to benefit all colostomy patients'.

Stewart Gale writes:
On the 28th October I completed the 2007 Great South run with the aim of raising money for charity and as a personal goal. For the past two and a half years I have had a stoma after emergency surgery for ulcerative colitis. Like most stories you tend to read it wasn't all plain sailing with a total of three operations and total of two months in hospital. At the beginning of 2007 I was finally discharged and set my self a personal challenge to prove to myself at the age of 28 and with an Ileostomy that there where no barriers to doing what you want in life. After six months of training three times a week, I managed to complete the ten mile run around Portsmouth in torrential rain and wind in 1 hour 38 minutes. I raised a total of £200 which has been split between two charities, the Colostomy Association and NACC.

In memory of John Isherwood...
We received a cheque totalling £475 in memory of the John Isherwood. John was a long time volunteer for the association and will be missed by many.

In memory of Oliver Hewitt...
Miss Hewitt sent in cheques totalling £24 which were given in memory of her father, the late Oliver Hewitt.

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

500 Club...

We still have spaces for those interested in joining the 500 Club. Prizes range from £25 to £1000.

Please contact head office on
0118 939 1537
for an application form

colostomy association

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

SASH

- The Sash belts are available on prescription and suitable for both male and female.
- All belts are custom made from information given on our Order Form and a hole is cut into the belt flange to fit your preferred pouch.
- No fittings are required. Belts are processed and mailed within two working days.
- For further information and to obtain an Order Form Freephone : 0800 389 3111

Security and Leakage Belt

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

"the ring of confidence"

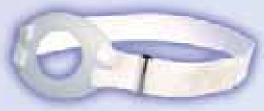
- This lightweight unobtrusive belt is designed to help eliminate leakage problems by holding the adhesive section of the pouch against the body during all activities.
- The belt also gives added security against the pouch becoming detached and will help to support the weight of a full pouch

Ref. no. SR103

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

Stoma Support and Hernia Belt

- The Stoma Support and Hernia Belt is made of a 50mm (2") non elasticized webbing attached to a restraining flange that fits between the bag and the adhesive section of the pouch.



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

Ref. no. S1

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

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

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

colostomy association

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

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

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

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

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

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

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

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

I want to become a ‘Friend’:

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

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

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

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

Office Address: 2 London Court, East Street, Reading RG1 4QL Tel: 0118 939 1537 Helpline: 0800 328 4257
E-mail: cass@colostomyassociation.org.uk Web: www.colostomyassociation.org.uk
Registered Office: Mill Cottage Polwheveral Constantine Falmouth Cornwall TR11 5RW Registered Charity No: 1113471

Donations & Standing Order Authority

colostomy association

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

Please return this form to: Colostomy Association 2 London Court, East Street, Reading RG1 4QL

Title: First Name: Surname:

Address:

Postcode:

Tel: Email:

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

To the Manager (Bank or Building Society)

Address:

Postcode:

Name(s) of Account Holder(s)

Account No: Sort Code:

Please pay:

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

Account Name: C.A. Ltd

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

The sum of: £

Amount in words:

Date of first payment:

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

Name: (IN CAPITALS)

Signature: Date:

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

giftaid it

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

Signed: Date:

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Convex ☐ **Flat** ☐
Beige ☐ **Transparent** ☐

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N.B Products with convexity should only be used after assesment from a stoma care specialist.

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Hospital Name: ____________________
Address: ____________________
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Postcode: ____________________
Telephone: ____________________
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Upfront

Do you, like me, have funny stories to tell about 'Life with a Stoma' or the use, or not, of 'Disabled' loos?

Would you be willing to share them? I would like to collect stories that make you smile, with a view to publishing them in some way. No one need be named so you could tell your story anonymously. If you can help, please contact me through CA. You can write it down and send it to CA or contact them for my telephone number or email address. I look forward to hearing from you!!

Gloria Hadfield

Looking for Travel Insurance?

We hear more and more stories of people with a colostomy finding it very difficult to obtain travel insurance. At head office we produce a list of insurance companies who will cover Ostomates. If you have had good service from a particular company please let us know by email: cass@colostomyassociation.org.uk or telephone: 0118 939 1537 and we will include them when we update our list.

Websites worth a look...

- www.stomadata.com
- www.stoma.fr

If you have found a website that has been particulary useful or has helped provide a product or service, please let us know via the usual channels.

Tidings

Dedicated to Colostomates and their Carers

Tidings is your Magazine...

Submissions:
If you have a story, article, letter or any other item you would like to appear in Tidings, please send them with any relevant photos or pictures to: The Editor, Colostomy Association, 2 London Court, East Street, Reading, Berkshire RG1 4QL or e-mail: cass@colostomyassociation.org.uk.

We will do our best to include them. Don't forget to supply us with your name, address, phone number and e-mail address, if you have one.

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

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

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

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.

How to contact us...

Colostomy Association
2 London Court, East Street, Reading RG1 4QL
Tel: 0118 939 1537
Freephone: 0800 328 4257
E-mail: cass@colostomyassociation.org.uk
Web: www.colostomyassociation.org.uk

Helpful
Groups & Organisations

Other Ostomy Support Associations...

- IA (The Ileostomy and Internal Pouch Support Group)
  Freephone: 0800 0184 724
  www.the-ia.org.uk
- Urostomy Association
  Tel: 01889 563191
  www.uagbi.org
- IOA International Ostomy Association
  www.ostomyinternational.org
- Gay Ostomates
  Tel: 0844 414 2356
  e-mail info@gayostomates.org
  www.gayostomates.org

Support Organisations for medical conditions...

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

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

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

RADAR
the disability network

NATIONAL KEY SCHEME

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

Colostomates are entitled to a key which will open 7,000 locked toilets around the UK. Some local councils will provide this key free, or for a small charge.

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

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

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