

Tidings

Summer 2007 Issue 6

Dedicated to Colostomates and their Carers



colostomy 

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inside...

join us for our
first national meeting
in association with Salts Healthcare

a day in the life
of a clinical nurse
specialist

diverticular disease
explained

plus all our
regular features...



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inside

this issue of Tidings

Dear Readers..

Travel proved to be a "hot topic" in our last issue of Tidings; we were inundated with requests for our travel certificate. As a spin-off from our article on travel insurance, we have been able to negotiate a scheme specifically for ostomates, the Colostomy Association Travel Insurance Policy. See the article on page 17.

Readers who have written to say that the magazine concentrates on people who have had cancer will be pleased to see that this time we include reference to a variety of other conditions which may lead to stoma formation. After cancer, the second most common reason for a stoma is diverticular disease, so we have an article which explains this condition on page 8. A lady who was born with bowel and bladder problems and has both a urostomy and a colostomy recalls her inspiring life story, and a thirteen year old gives a candid account of her diagnosis of Crohn's disease and subsequent colostomy.

Calls on the helpline also often ask for information about colostomy reversal and indeed in this issue of Tidings we have letters about this subject on both the Dear Nurse and Readers' Writes pages. So in our autumn edition we are planning to include articles written by stoma care professionals explaining what the different types of reversal operations entail and the pros and cons of opting for surgery. We would also like to hear from readers who have had reversals about their experiences - both good and bad.

You will see from the announcement on pages 5 & 6 that the Colostomy Association is holding a national meeting sponsored by Salts at Sutton Coldfield on Thursday 6th September. The editorial team will be manning a stand at this event and we hope to meet as many of you as possible so you can tell us what you would like to read about in your magazine, Tidings.

Best wishes,

Rosemary Brierley
Editor

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

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

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

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From being very poorly to fighting fit in twelve months...



I would like to share my husband's story with your readers. This is mainly for the people who are frightened at the beginning of a difficult journey, and also to acknowledge the amazing recovery that is possible.

Tony was a healthy, active fifty-five year old when he was diagnosed with bowel cancer in September 2005. We were both shocked, and in fear of the treatments planned - and the outcome.

After many tests and various scans, we were told there was only one tumour, very low down in the bowel, but it was a large one.

So twenty doses of radiotherapy and a month of chemotherapy commenced. The treatments ran concurrently, and slowly

wore Tony down until he became poorly and stayed in bed for most of December. To think, it wasn't the cancer making him poorly, it was the cure!

In January 2006 Tony started to feel better. He walked every day and gradually built himself up to be as strong as possible ready for his surgery. A scan at this point showed the tumour had shrunk by 50%. Hurray for radiotherapy and chemotherapy!

The following month the surgery went ahead. Tony had his anus removed completely, and his colostomy 'installed'. After two weeks in hospital I brought him home. We were both nervous and hesitant of our new way of life. The nurses visited; their support and understanding calmed us down, and we slowly settled into our

new routines. We had a lot to learn, but there was always someone to offer guidance and advice.

Tony made a steady recovery and soon became confident in caring for his stoma who we christened 'William' (mainly after the mischievous 'Just William' but a little bit after William the Conqueror).

Six months after the surgery Tony had a scan and blood test which came back ALL CLEAR. After holding our breaths for months, we started to breathe again. It was June 2006 when Tony went back to work. He was given a lighter job on the advice of the company doctor and really enjoyed getting 'back to normal'. His employers and colleagues have shown great understanding through a very difficult time and so have all our family and friends.

In September 2006 Tony flew to Austria for a few days with our son, Chris. He was a bit apprehensive but with Chris to lean on, off they went. They had a wonderful confidence boosting holiday. I think the enclosed photograph reflects how far Tony has come - from being very poorly to fighting fit in twelve months.

It will be a year neither of us will ever forget. We still have difficult moments with William, but nothing that we can't deal with and usually manage to laugh at. Tony thought a permanent colostomy would mean the end of the world and really feared it, but it's not. It's just the start of a whole new chapter.

The cancer took a year out of Tony's life; the colostomy gave him a second chance.

Alison Hunt

Name Your Stoma Competition...

In the last issue of Tidings we asked you to help us decide on the winners. We have counted your votes and here are the results.

The Best Name

Winner	The Privy Purse (sent in by S. Grimshaw)
Second place	My Appliance of Science
Joint third	Little Iffie
	Percy

The Best Letter

Winner	Polly Pocket (sent in by M. Evans)
Second place	Dooper
Third place	Colin

Congratulations to both winners who each receive a £25.00 M&S voucher.

Thank you for your entry, Emily (aged seven)
Hope you enjoy spending your £5.00 W.H. Smith voucher.





You are invited to the first
Colostomy Association National Meeting
“Changing Times”

Thursday 6th September
At Ramada Jarvis Hotel
Penns Lane, Walmley, Sutton Coldfield B76 1LH

If you would like to attend, please complete the slip below and return it to:-

Colostomy Association Meeting
c/o Salts Healthcare, Freepost RLUZ-XJBU-BZAH,
Birmingham B7 4AA. (no stamp required).

In association with Salts Healthcare



I would like to attend the Colostomy Association National Meeting

I will / will not* be bringing a guest (*please delete as applicable)

Name:

Address:

Postcode:

Telephone:

E-mail address:

We will post your ticket/s and further details to you nearer the time

Registration opens at 9.30am,
conference starts at 10.30am prompt

The meeting will include:

- Talks by a surgeon and nurse on hernias
- Update on the Department of Health's Consultation Document regarding the provision of stoma care products and services
- Find out about the new Colostomy Association and its plans for the future
- A chance to see the latest Salts ostomy products and accessories
- An opportunity to meet other colostomists
- Lunch and refreshments will be provided
- Free coach travel available from a number of cities



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COACH TRAVEL

Please tick if you would like a seat/s booked on one of the coaches

- Manchester:** 7.00 am at Chorlton Street Bus Station (next to Britannia Hotel)
- Bristol:** 7.30am at Anchor Road, Bristol City Centre
- London Heathrow:** 7.00am at Hatton Cross tube station
- M25 East:** 7.00am at Lakeside shopping centre
- Leeds:** 6.30am at West Yorkshire Playhouse
- Sheffield:** 7.15am at Meadowhall Coach Station

Please note: Numbers are restricted and will be allocated on a first come first served basis

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Diverticular Disease

By Peter Cartwright MSc MA



Peter Cartwright has an MSc in Microbiology and an MA in Sociology. He also has eighteen years experience of working for patient and self-help associations including the N.A.C.C. and has published books on ulcerative colitis and Crohn's Disease.

Readers who had their stoma due to diverticular disease may be interested in the book 'Coping with Diverticulitis' by Peter Cartwright which is published by Sheldon Press at £7.99p. ISBN: 9780859699853



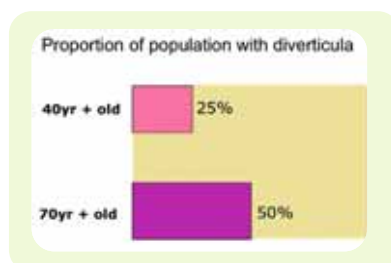
In 2002 Tidings carried out a survey of its readers. Of the 2,800 colostomates who responded, 10% gave diverticular disease as the reason for having their stoma.

Readers Survey 2002

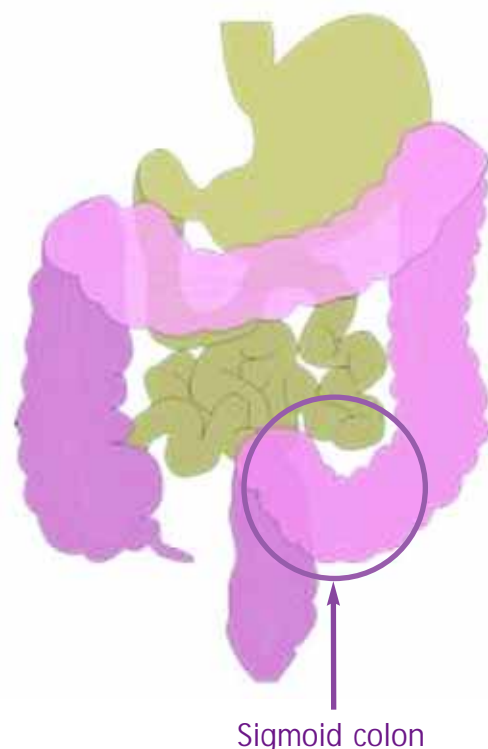


What is diverticular disease (DD)?

DD develops when small protrusions (sacs) appear in the wall of the large intestine – usually in the sigmoid colon. These protrusions are known as diverticula, and are the size of small grapes. They are surprisingly common. Within the UK, about a quarter of the population over the age of forty have diverticula, and this proportion rises to about half of all British people over seventy.



Thankfully, only about 15% of people with diverticula ever experience any symptoms from them, but this still leaves quite a large number of people affected. Within the UK, about 450,000 people have symptoms from DD at any one time, with about 60,000 new cases a year. Hospital admissions for serious cases of DD are about 17,000 per annum, and more than 4,000 people die each year from severe complications of DD.



Illustrations reproduced courtesy of Peter Cartwright MSc MA. ©2007.

Symptoms

The main cause of symptoms from diverticula is the development of inflammation in the region of a diverticulum. The inflammation is known as diverticulitis and is probably caused by faeces lodging in the neck of the diverticulum and rubbing against the nearby tissues. Diverticulitis causes continuous abdominal pain and altered bowel habit (constipation or diarrhoea, or alternating between the two).

Diverticulitis is treated by antibiotics and a low-fibre diet. In about two-thirds of cases of diverticulitis, the person has no further trouble from their diverticula. However, if there is a recurrence of symptoms, a complication of diverticulitis, such as an abscess, may develop.

Complications of diverticulitis lead to severe pain, sometimes sufficient to warrant admission to hospital. Intravenous antibiotics and bowel rest (intravenous feeding) usually overcomes the problem, but in about a quarter of cases surgery is undertaken. Surgery is necessary because there is a risk of perforation of the colonic wall and dangerous peritonitis developing. Surgery involves the removal of the damaged area of intestine and the formation of a temporary colostomy. After some months, a second operation reconnects the healthy parts of the large intestine and the colostomy is closed. In about a third of cases, the patient decides to keep the colostomy and to forego a second operation to avoid the discomfort and associated risks.

Although most symptoms are caused by diverticulitis, in about 15% of cases the first symptom is haemorrhage (copious bleeding), which is unconnected to diverticulitis. The haemorrhage, from the back-passage, is usually painless. It can, however, be very worrying as it usually occurs without warning and its cause is initially uncertain.

People affected are taken urgently into hospital to undergo various tests, to confirm the cause. If it is caused by DD,

the most likely explanation is the rupture of a blood vessel stretched over a diverticulum. This usually occurs at diverticula in the ascending colon, where diverticula tend to be larger. In most cases of diverticular haemorrhage, the bleeding ceases of its own accord. If bleeding continues, then the affected area may have to be surgically removed.

The cause(s) of DD

The main cause of DD is a lack of fibre in the diet. This conclusion has been reached for the following reasons:

- Diverticula of the intestine are a phenomenon of the developed Western world, and started to appear at the beginning of the twentieth century when food products, such as bread, were refined to reduce the fibre content.
- The diet in populations with no diverticula, such as rural Africans, has a much higher proportion of fibre, which is reflected in the weight of daily stool excretion being four times greater than among Europeans.
- People with diverticula tend to have significantly less fibre in their usual diet, compared with people without diverticula.

Other factors in the cause of diverticula are thought to be:

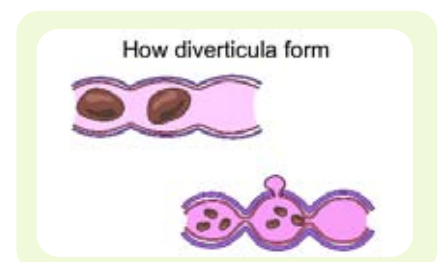
- Ageing
- Red meat consumption
- Lack of exercise

Of these three secondary causes, the strongest evidence is found for the ageing process.

How are diverticula formed?

As a child, do you remember having a birthday party at home with balloons? The following morning you would find that some of the balloons were partly-deflated, having leaked most of their air overnight. I remember playing with these balloons by holding one in my hands and squeezing. The effect was that a bit of the balloon would pop out from a gap in my hands. A diverticulum forms in a similar way. Just as part of the balloon was forced out of my hands by the pressure created by squeezing, so diverticula are formed by high pressure within the large intestine.

But why is there high-pressure within the large intestine? This is where dietary fibre comes in. Dietary fibre is the part of food that is not digested by human enzymes. Therefore, if your diet contains plenty of fibre, there will be plenty of substance remaining as the undigested part of food reaches the large intestine. The bulkier the faeces the more easily the content is moved about by the muscles in the wall of the large intestine. If, however, there are only small amounts of fibre in the faeces, troubles start.



The main function of the large intestine is to remove water from the faeces, partly because water is an essential part of the body and partly because solid faeces are easier to control than liquid faeces. On average, the large intestine takes two days to move faeces along its length. This involves the muscles of the outer layer of the intestinal wall contracting. Mostly the muscles will push the faeces backwards and forwards in the same area of the

Diverticular Disease

colon, and then occasionally there will be one big push in which the faeces are pushed substantially along the length of the colon.

If, however, the person's diet contains little fibre, the faeces will contain little substance in the large intestine, and the colonic muscles will strain. A consequence of the colonic muscles straining is that flexible muscle proteins change their characteristics and become thicker and less flexible. The combined effect of these changes is that the sigmoid colon develops a corrugated shape (concertina-like). This means that when the colonic muscle contracts to move the contents, high-pressure compartments are formed within the colon. The high pressure is released by the formation of diverticula, which involves the forcing of the inner layer of the intestine (mucosa) through the muscle layers of the colon.

As people age, their colons become a little less flexible and this may increase the likelihood of diverticula forming. The apparent benefits of increasing exercise and reducing red meat consumption do not have clear explanations. It is possible that regular exercise may provide a better blood supply to the colonic muscle and may reduce the tendency to inflexibility over time.

Prevention of DD

The key to preventing DD lies in eating a high-fibre diet. Not only is there good evidence that such a diet reduces the likelihood of developing diverticula, but also that dietary fibre reduces the risk of developing symptoms in people who already have diverticula in their colon.

Dietary fibre is absent from meat, but is present in cereals, vegetables and fruit. Most fibre is found in the rigid walls that surround the cells that make up plants.

Of the different categories of food, those with the highest amounts of dietary fibre are shown in the table below:

Grain (cereal) products



Whole grain wheat, rice and corn (maize) products, such as bran flakes, shredded wheat, brown rice and wholemeal bread. Other grains are oats, millet, barley, sorghum and rye.

Fruits



Avocado, apricots and unpeeled apples and pears.

Vegetables



Cabbage, broccoli, brussel sprouts, cauliflower, carrots, celery, pumpkin, sweetcorn, spinach, asparagus stems and baked potato with skin.

Legumes (peas and beans)



Almost all types of legume, including garden peas, French beans, kidney beans and baked beans.

Nuts



All nuts, especially almonds and peanuts.

Eating plenty of whole foods not only increases the amount of fibre in your diet, but also gives you major nutrients, as well as minerals and vitamins. Fibre has other health benefits such as reducing cholesterol in the bloodstream.

There are two main difficulties in increasing the amount of fibre in one's diet. Some people live fast-paced lives and may not have enough spare time to easily prepare and cook whole foods. Furthermore, people in the UK should, on average, be looking to increase their dietary fibre consumption by between 50% and 100%. This is a substantial amount, and it is not always easy to change one's eating pattern to achieve this. One way of easily increasing fibre intake is to add bran supplements to your usual foods. Bran is approximately 40% fibre, compared with about 2% in most plant foods. Wheat bran consists mainly of insoluble fibre, which is a type of fibre especially helpful in counteracting diverticula development.

The future

Recent statistics have shown that DD symptoms are continuing to rise in frequency within Europe. Over a recent ten-year period, the increase has been more than 50%. Most of this increase is caused by people living longer, as the older you are the more likely you are to have trouble from DD. But about a fifth of the increase is unconnected to the ageing population, and may be due to increased consumption of low-fibre foods such as ready-made meals and 'junkfoods'.

It is therefore more important than ever that the younger generation is advised of the importance of high-fibre diets. ■

Diverticular Disease - A Readers Experience



Andrew Legg

I woke early on Christmas day morning to see what gifts I had received. Well strictly speaking I "came round". My gifts were not as usually expected at Christmas – an eleven inch wound down the centre of my stomach, thirty-one staples and a stoma and colostomy bag! Perhaps I had better start at the beginning!

It began on Sunday December 17th 2006 during the evening. I had severe lower abdominal pains which got worse as the night progressed. I am not, by any means, a hypochondriac but by three in the morning I was on the phone to NHS Direct for guidance. I was advised to make an urgent appointment to see my GP. By 9.30am on Monday 18th I was diagnosed with acute Diverticular Disease and prescribed an antibiotic. I was in too much pain to drive to work so took to my settee in front of daytime TV – normally enough to send any able bodied individual back to work! By Thursday the pain was worse and at a return visit to my GP I was given a letter to take to the City Hospital in Nottingham for a "few tests".

Naturally being an innocent in all this I drove to the hospital confident that I would be home by lunchtime. Little did I know I was in for the duration! I had blood tests, X-rays and eventually a CT scan. By mid afternoon I was getting worried that my car – with a four hour parking fee - would be getting clamped or towed away. The ward sister kindly rang security and I was relieved to be told it was safe. However by Friday morning –

yes I was still there – I had to arrange for a friend to come and take my car away as I was told in no uncertain terms that I was going nowhere. The CT scan had shown a tumour on my large colon that was bursting and about to infect me with peritonitis.

Shortly afterwards an ambulance transferred me to the Queens Medical Centre where I was placed in a specialist ward. As Christmas was only two days away the consensus was that I would not be operated on until after the festivities. How wrong! At about 10pm on Christmas Eve I was wheeled to the operating theatre and the next I knew was when – as I said above – I awoke with my Christmas gifts!

I am a reasonably fit sixty-six year old male still working full time in quite an active profession so all this was a great shock to me and my system!

Luckily there were no complications after the operation, which I learnt was the Hartmanns procedure and I was soon instructed by the Stoma Nurse team how to manage my colostomy bag and my diet.

Because of the Christmas holidays I was on tenterhooks for days until the Path Lab reassured me that the tumour was benign and that I should make a full recovery with no side effects.

I was discharged on 4th January this year and was at home recuperating for nearly six weeks. I returned to work part time and gradually over three or four weeks returned to full time work. I managed quite well with my colostomy bag but was anxious for a reversal, so when I realised that my company health scheme would fund the procedure privately I jumped at the chance.

In late April 2007 I had a colonoscopy to check if everything was in order for the reversal and I was booked in on 3rd May – just over four months from the original operation. It was decided that a

laparoscopic technique would be appropriate as this was less intrusive and would enable me to be up and about far sooner. My consultant in Nottingham was superb and talked me through the procedure in great detail and I was happy to give my consent for the operation to proceed.

I was in theatre at 8am and back in my room just after noon. I must thank the team at Park Hospital in Nottingham for their fantastic skill and expertise in making it all possible.

Three days later on Sunday 6th May I was allowed home to recover again. On 13th May I had my first batch of wound staples removed, had a reasonable diet and was able to walk around quite well. I was still in some pain but I felt far better than I did in January after the Hartmanns.

I had a mild scare two days later with a sudden bout of diarrhoea and passing blood but was reassured by both GP and Consultant that this was quite normal and predictable and that I was not to worry unless the symptoms continued. Fortunately after a couple of days I was back to normal and very relieved.

I have to return to outpatients for the remaining staples to be removed and am likely to be back at work in three to four weeks time.

If there are any developments I will keep you informed.

I am writing this in the hope that it may help others in the same circumstances who may have been as frightened as me and not know what to expect!

Andrew Legg

Young Colostomates...

I am 13 years old and have Crohn's disease. It all started when...

I finished primary school in 2004 and was looking forward to the summer holidays and my new start at Belle Vue Girls' School. The week I left my old school I began to get lower back pain. I took painkillers and the pain went away but only for a little while. A week later it was back, much worse than before; I could not sit down or sleep properly. Mum took me to the GP, who examined me and said that the symptoms might mean an abscess that would probably have to be popped. She prescribed some antibiotics to make it surface quicker and said that I'd be fine in a month.

Things were OK for a while then I noticed some yellow discharge when I went to the loo. The GP inserted an instrument into my bottom. When she removed it and I was flinching with pain the doctor said, 'Salma, stop fussing. There's nothing there!' I found this absolutely ridiculous and shocking because even though I was an eleven year old I still knew what was up with my body and what wasn't!

The following week my bottom area was red and sore so she gave me some more antibiotics and referred me to the hospital. Back home I was sick with fever, vomiting and diarrhoea but there was still nothing to indicate that there was an abscess. On Sunday 22nd August after an awful night my parents decided to take me to A & E. Normally you have to wait four to five hours, but this time they took me straight through to see a doctor. When he examined me he confirmed it was an abscess and it was too big to just burst - plus this wasn't an ordinary abscess: it was facing inwards so there were no marks on the outside. I had to have the operation at 7pm that evening. I thought that I would be out in a week and hopefully go to school as normal but it didn't end there...

On 3rd September I was discharged from hospital. After three gruesome operations I was left with a huge drain - going to school was out of the question. So much for my "first day at high school" - that's something

I'll never experience. I had home tuition instead - twice a week for five hours. The problems were still there. I had difficulty going to the toilet; it was very painful and stressful. I never put back the weight I had lost. It was a long haul because the abscess was very nasty: three inches deep and it had made a tear in my anus. The doctor warned us that I may need a colostomy.

I stayed at home until January 2005 and then I decided that I wanted to go back to school. The school nurses and teachers were very helpful and there were excellent facilities. I had a medical card which allowed me to use the toilet in the middle of lessons etc. After spending a fair bit of time catching up I was on track and put back on the Gifted and Talented list, a group of pupils above national average. I struggled trying to keep my toilet problems out of school hours. When I got home I didn't have the time to even say 'Hi' to Mum; I just rushed to the loo.

I had times when for two weeks I was pain and trouble free. Then there was a week where I would have throbbing pain in my bottom and a while later I would have lots of pus coming out of the drains. I had various examinations under general anaesthetic and the doctor would remove and replace drains to adapt to the flow and size of the abscess. It was healing, but it was taking too long and I was, and still am, running out of patience. Although before I had felt hollow on the right hand side of my bottom it has somewhat managed to fill the gap with some parts still remaining. I became friendly with all the nurses on Ward 2 at Bradford Royal Infirmary especially the nurse who visited me every week to do the dressings. I had to change it twice a day and also wear a sanitary towel 24/7.

Anyway on 18th July 2006 I had another of my many hospital appointments; this time it was to get the results of the biopsies they had taken at my last operation. They did this every time and they always came back clear, so what was the big deal this time? Well it was a big deal this time because I had Crohn's disease. The doctor said, 'It's a disease of the

digestive system anywhere from the mouth to the anus. It cannot be cured but there are many treatments so I am referring you to a gastroenterologist who is an expert on this condition, but I will still treat you when you need surgical procedures. How do you feel?' While he was babbling on I broke down in tears. So many things were going through my head: What's that? When did I start having it? Will I get better? Will I stay like this? Forever? Will I die? Well I came to find out I won't die - so that was a relief. The Crohn's was situated around my lower colon, rectum and anus. I was devastated. What would I tell everyone? They kind of figured it out soon because that summer was also ruined like the past three. I had every symptom in the book: fever, sickness, diarrhoea. A rash that was thought to be eczema came out of the blue because of the heat-wave but it turned out it was only a rare rash that some people get as a result of Crohn's. To carry on the list I developed a urine infection then I got to the stage where the old dry skin from the 'eczema' was peeling away; my bedroom carpet was disgusting. I hated every bit of it - and it was all because of Crohn's.

I had an appointment to see the gastroenterologist on the 11th October. A lovely person to talk to plus she was a woman so I could talk about my problems without having a red face like I did when it was a male doctor. I started medication, Metronidazole and Mesalazine, which were anti-bacterial and anti-inflammatory drugs. These made a significant difference; I was feeling healthy and full of life but going to the toilet was still painful. Later the next month I had a small barium meal and a colonoscopy. The results were fine: only a spot of Crohn's in my colon.

After that I was told I couldn't carry on with life as it was. I needed to try things to see if they worked out and made a difference. Steroids were out of the question because I was still growing - I mean I haven't even started growing! So it was either a colostomy or this new drug called Infliximab. However, this new drug was quite strong. It did do the job

Young Colostomates...

but that didn't change the fact that it was risky. For the majority of people it was successful, but the effect it had on teenagers and youngsters was not known. So I was advised not to opt for that. Even if it did work miracles I wouldn't risk my life - No way Jose. So I was left with a colostomy - Yes that again. So many times I had been offered this and I refused because I thought it was a bad thing. Also I didn't know that this whole thing would turn out to be more than just an abscess - that it would be Crohn's. It's weird but the doctors suspected it all along but never let on until it was definite.

So the date was set Wednesday 28th March 2007 - first on the theatre list. I was really nervous. I'm not usually because I know the drill. It's in you go to the theatre, the doctor has a good look, takes biopsies, takes out the dead skin and gives it a good clean. But this time it was different. I would be different when I woke up. I would have changed.

It was OK... when I woke up they had given me an epidural so I was "right

up there on Cloud Nine". Yeah, it was the drugs. I was quite happy and jolly and the nurses warned me, 'Don't be surprised if you're feeling down tomorrow.' And boy was I down, I was downright moody! I had changed the bag myself and seen the stoma; the swollen pink blob looked huge on my skinny body. For some reason after seeing it I kind of regretted having it done. Maybe I was confused but I seemed to fear what was to come. A doctor came on the Friday and confirmed I could go home, and of course I wanted to, so I packed my bags and that night I was at home in my own room, in my own bed.

Well, four weeks on I feel brilliant! The discharge from my bottom is less and I've got two drains to make sure that no pus is held back. I manage the stoma fine; I change it once a day and empty it if needed throughout the day. I have recovered well from the operation. It took me two weeks but the thing that worries and surprises me is that the three year old abscess is still with me. I chose to have a stoma and I think it was the right decision because I don't worry

about toilets anymore. I am cheerier than usual as my friends have noticed. Even my dad mentioned this morning that I am less moody and I seem to have put on weight around my face - well it's either that or my sore mouth from my braces! Now I seem to want to do things: I want to go out. I want to go to school. I want to join in clubs, activities, etc. My mum said, 'Just a little more patience and you'll get there.' So hopefully, everyone, keep your fingers crossed.

Fourteen operations, a million and one appointments and lots of pain later I am finally on the up...and I have a HUGE smile glued to my face...

Salma Ahmed

Salma would like a pen-pal, preferably about the same age as herself. If you would like to write to her, send your letter to head office and we will pass it on.

A Date for your Diary...

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



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

The 'Breakaway Weekend' is to be held on 17th-19th August 2007 at YHA, Bryn Gwynant, Snowdonia.

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

Details about the weekend...

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

BREAKAWAY!

Break Away Weekend 17-19th August 2007

- The UK's First Family Activity weekend £130pp including a free t-shirt
- Bringing together young people living with bowel/bladder diversions and their families
- REAL Adventure Activities - AALA license; qualified and experienced instructors
- Supported by the Ileostomy, Colostomy, Urostomy Associations and the NACC
- Funding Available
- Cost includes all meals & activities

Wind...Ballooning, Odour and Noise

Everyone produces wind, but for colostomates, who cannot control when it is released, it can be a problem. We put your questions about wind (flatus) and in particular odour and ballooning to Dr Rory Smith from Welland Medical Ltd.

What causes wind?

The major factor is undoubtedly gas production as a result of the breakdown of food. This is a completely natural process and a direct consequence of digestion. Stomach acid, enzymes and bile all contribute to the breakdown of our complex food into simpler chemical molecules, some of which are absorbed and the remainder pass through the intestines as waste. The continued breakdown of the waste in the gut liberates a complex mixture of chemicals as a gas. The precise composition and volume of flatus is directly affected by diet.

Some foods such as cabbage, cauliflower, sprouts, beans, peas, onions, nuts, cucumber, carbonated drinks and beer can increase the amount of flatus which is typically about 500ml per day. Some of these and also eggs, garlic and asparagus can generate odour because of the breakdown products produced.

At present there is very little that can be done about the embarrassing problem of stomal noise. However we received the following news bulletin from David McDermott, Director of Meditech Technology.

Silence stomal noise, restore privacy and dignity

Most patients report that an especially troublesome aspect of life after a colostomy is the loss of privacy of bowel movements. The various noises produced as the colon expels solid, liquid and/or gas are unpredictable and uncontrollable. This is a major inconvenience often adversely affecting quality of life, limiting social engagement and undermining even the closest personal relationships.

A team of medical and business professionals has just completed research at Northwick Park Institute for Medical Research into how to control this troublesome post-operative side-effect of a colostomy. They have established

What is the best way to combat odour?

Generally the type of odour produced falls into one of two broad groups. Those containing sulphur from the breakdown of certain amino acids contained for instance in eggs. The other group of complex organic compounds containing oxygen and/or nitrogen (butyric acid, indoles and skatoles) from the breakdown of substances found in certain green vegetables and fish. Methane, nitrogen and carbon dioxide are also present in flatus.

A well designed activated carbon filter on a stoma bag should deal with the broad spectrum of odours contained in flatus as the gas flows through and is vented from the inside of the bag into the atmosphere. The type and density of the carbon and the length of the pathway through which the gas travels are all factors in the effectiveness of the deodorization process.

precisely how stomal noise is produced and how to silence it with a simple, inexpensive, disposable device compatible with current stoma-wear! Funding is now urgently required for prototypes.

Research and development to date

What causes stomal noise?

Understanding how it is created is essential for the development of devices for the elimination of this noise. It was established that gas became trapped at the point where the stoma narrows as it breaches the peritoneal wall. Normal peristalsis causes a build up of pressure until the stoma's natural elasticity is compressed and a small conduit is created allowing the air to escape. The extent of the pressure build-up determines the speed and sound of the evacuation. It is not possible to control the activity of a stoma and regulate the release of this build-up of pressure.

Potential ways to silence stomal noise

The team developed a number of safe and effective ways of regulating the release of gas so that it made no noise. Clinical

What is ballooning?

If the rate at which an individual produces flatus is greater than the pre-set flow rate of the filter, the bag will inflate and the pressure in the bag can be uncomfortable and cause the bag to be obvious under clothing. This is referred to as ballooning.

The effect can be made worse if the filter is partially blocked by waste in the bag. This has the effect of reducing the flow rate through the filter and exaggerating the problem. Many manufacturers provide some form of filter protection to reduce the effect of filter blockage.

If ballooning is a problem for the individual, careful attention to diet to control the rate of flatus production, and selection of a bag with a filter flow rate that provides a good match to the rate of flatus production is the key.

Rory Smith

devices have been designed that are compatible with commonly used stoma-wear and do not impede the stoma's normal functions.

Next steps

Prototypes and clinical trials

To date, all research and development has been funded by a combination of private sector investment and public sector funding (SMART award) but this is now exhausted. Completion of this next stage – refining the design, manufacturing prototypes, conducting clinical trials and obtaining regulatory approval – will require further private sector funding. The company which has pioneered this research is now looking for an investor or a small number of investors, who will help bring relief to millions of patients worldwide.

To express your interest in investing, please write or email:

David McDermott
Director

Meditech Technology

24 Grays Inn Road,
London WC1X 8HP

meditech@jointventure.demon.co.uk

“Free yourself. Free the planet.”

(FREESTYLE® FLUSHABLE USER)



If you often feel that trying to find somewhere to dispose of your pouch is ruling your life, you're not alone. However, with new improved Freestyle Flushable this no longer needs to be the case as it simply flushes away.

FreeStyle Flushable has a new inner liner which is now even easier to remove and flush down the toilet. On top of which the inner liner is biodegradable so you can be sure you're doing your best to help the environment.

New improved Freestyle Flushable – helping you enjoy more freedom in your life and free the planet.



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Update...

on new stoma care products and services

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

CliniMed has just added a new two piece product to its Freestyle Range.

Freestyle 2 Piece has a new low profile, double security coupling system. The pouch ring fits snugly around the raised ring of the base plate. The coupling is made doubly secure with an adhesive on the pouch ring which greatly reinforces the seal. This gives ostomates reassuringly high levels of security together with the comfort normally associated with a one piece pouch.

Freestyle 2 Piece is available in two ring sizes and three pouch sizes: midi, maxi and maxi plus. The pouches are available in both closed and drainable versions and have a new, more modern beige coloured outer pouch fabric.

Oakmed have introduced a range of pouches and wafers designed to meet individual needs.

With three different types of wafer to choose from, alginate, microskin and hydrocolloid, colostomates can select the most suitable for their skin type.

Alginates are clinically proven to help heal sore skin. The wafer is bioactive so it actually helps to prevent as well as cure this problem. The wafer is also impregnated with added vitamin E which helps protect the skin from free radicals.

Microskin is the thinnest wafer available.

Hydrocolloid wafers are extremely flexible and comfortable.

All wafer types are available in one or two piece systems with a range of pouch sizes. **Samples can be obtained by calling Freephone 0800 592 786**

Dansac have launched a discreet closed pouch to suit your lifestyle.

As part of their commitment to improving products and services for people living with a stoma, Dansac Ltd has launched an innovative new collection of one piece closed pouches. The Dansac NovaLife™ range has been designed to offer greater comfort, convenience and choice and features a completely new pouch and barrier design.

The unique pouch shape is achieved by moving the Dansac Nova Twin-Filter from the top of the pouch to the side, and placing it within a protective chamber. This then makes it possible to position the barrier closer to the top of the pouch resulting in a low-cut profile. A special heat seal prevents sagging and creates a more discreet pouch which is less visible under clothing. The slim-line barrier shape also optimises the adhesion around the stoma, moulding to the contours of the body and improving security.

The **Dansac NovaLife™** range offers both comfort and freedom of movement while the discreet shape allows a greater choice in what you can wear.

If you would like to receive a free sample of the Dansac NovaLife 1 Closed, or are interested in further information about the Dansac range of products and services, then please contact Dansac on Freephone 0800 581117.

Hollister Ltd is pleased to announce the introduction of their new **Educational Theatre DVD for Ostomy Patients**.

This instructive DVD can be used by nurses both as a technical guide and for training purposes. It gives patients and their families an understanding of ostomy surgery and demonstrates the use of stoma appliances.

The modular format of the DVD is a deliberate design, intended to enable personalisation of the Educational Theatre by stoma type and product used (one or two piece system).

Part 2: "The Patients' Perspective" will be released later in 2007.

Delivery companies willing to send stoma supplies abroad
Addendum:

In our last issue we omitted to include the SecuriCare Medical Home Delivery services (0800 585125).

SecuriCare are happy to make a free-of-charge overseas delivery to clients who are away for more than four weeks.



Dedicated to Colostomates and their Carers

Information on new products and services received before 20th August 2007 will be considered for inclusion in the next issue of Tidings

Ray Goddard
Managing Trustee

New Travel Insurance Policy for Ostomates



In the last issue of 'Tidings' we published an article which was designed to provide independent advice on the perils and pitfalls of arranging travel insurance. We received an amazing response and have, therefore, carried out some further investigations to assess the range of prices that insurance companies charge. Quotes varied widely and rose considerably when the pre-existing condition (having a colostomy) was mentioned. Colostomies are widely misunderstood by the travel insurance industry and there is no doubt that our members are being prejudiced against.

It is, therefore, with delight that we have been able to negotiate a specific Travel Insurance scheme designed for Ostomates – The Colostomy Association Travel Insurance Policy (CATIP).

In researching this initiative we wanted to ensure three very important features for our members: -

- Price competitive
- Immediate policy issue
- Wide insurance protection with a quality and secure insurer

We have been able to satisfy all of these points, and more, with the introduction of CATIP; the Association will also receive commission on every policy written. Every ostomate and, indeed, families friends and contacts can buy a policy directly on line. We would encourage everyone to get the message out that CATIP competes with any other travel policy.

With CATIP we are moving from a situation where insurers run scared of us, or charge ridiculous premiums, to one where our standard terms are considerably better than most policies available, even for a person without a pre-existing condition. This is best illustrated by providing a specific example: -

We requested annual travel insurance for a couple in their 50's, on a world-wide basis including USA and based upon having a Colostomy for 14 years. The "standard" rate was £109.99, which increased to £315.89 once the pre-existing condition was

disclosed. Under the CATIP scheme the premium would be £127.72 based on full disclosure with complete protection and no restrictions.

To provide a full comparison of prices, we obtained quotations from a wide range of insurers as detailed below:

Age Concern	£188
All Clear	£199.94
Free Spirit	£204.80
Worldwide	£219
Direct Travel	£145

A further ten quotations were obtained but all did not include cover for pre-existing conditions and were in excess of the CATIP costing.

All prices quoted were correct as at 26 April 2007.

You will be able to obtain immediate quotations, assess the full extent of cover, make your selection and purchase cover via our own web site. Your policy will then be e-mailed to you. The scheme is underwritten by Europ Assistance who are wholly owned by Generali and one of the world's leading insurers.

Our insurer will view all medical conditions sympathetically; they will even consider full cover where there is a terminal diagnosis. The wearing of a colostomy bag does not constitute a pre-existing condition and normal terms, as indicated on our web site, will be offered. The travel cover will, therefore, apply full medical cover without penalty. The obvious advantage to ostomates using our dedicated travel insurance scheme is that there can never be any question or barrier put up by the insurer as a result of your stoma. If you are suffering from any other condition, taking medication or undergoing treatment, then this can be disclosed to the medical screening line as indicated on the web site. They will consider all such conditions.

The Colostomy Association Head Office has very little involvement administratively with CATIP and we would ask that you direct any queries or problems to Peter Martin (01202 850142) who is actively involved with the Colostomy Association and is tasked with ensuring that the scheme runs smoothly.

Summary

CATIP is long overdue. We should no longer tolerate the outdated approach shown by the insurance industry in the evolving medical world.

Do not accept travel insurance offered by a travel agent or under a credit card.

Our premiums stand up to any competition with the added bonus that no individual with a colostomy will be treated unfairly.

Such are our premiums that we would encourage members to ask others to visit and hopefully take out a policy through us. The policy can apply to non-members as well as members. This in no way detracts from the specialist facility because we see this avenue as an income stream such that we can supplement our all-round service.

CATIP gives you:

- Speedy quotations and policy issue.
- Competitive prices.
- All policies can be bought securely on line.
- Generous cover limits.
- Security and re-assurance with a world-leading insurer.

CATIP gives us:

- An income earning stream for the Colostomy Association.
- Satisfaction because there is a real solution to a real life problem.
- A certainty that, as ostomates, we are not prejudiced against.

If you would like to obtain a quotation for a Travel Policy please refer to the CATIP page on our website www.colostomyassociation.org.uk



A Colostomate's Guide to Welfare Benefits

In itself, a colostomy is not considered a reason to qualify for a state benefit. However, if you are on a low income or problems with the stoma mean that you are unable to work, then you may be able to claim. If the condition which led to a stoma persists or you have another medical problem you may be entitled to a disability allowance. We asked Anthony Gray, who worked for twenty years in local government and whose job included advising the public on benefits, to explain. Anthony has been a colostomate for seven years.



Anthony two years after his colostomy operation. His recovery was slower due to MRSA. Anthony says, 'I was glad to see 50 and my two sons grow up.'

A colostomy on its own will not necessarily entitle you to any of the non means-tested benefits. However, if you are unable to work or need care because of the medical condition that led to your stoma or have another disability or illness, you may qualify. It is always worth seeking advice if in doubt.

For some people, treatment for bowel cancer involves pre-operative chemotherapy and/or radiotherapy, surgery and colostomy formation, post-operative chemotherapy and/or radiotherapy and possibly a reversal, all of which can extend over a considerable period of time. Those who have been in regular employment will be entitled to Statutory Sick Pay. After 28 weeks this will be replaced by Incapacity Benefit, which continues until a doctor confirms fitness to return to work.

Disability Living Allowance is for people under 65 who need help in looking after themselves and coping with a medical condition. There are two parts: The care component is for those who need help at home with personal care i.e. washing, dressing, changing a colostomy bag etc. There are three rates, depending on how much care is required. The mobility component is for help required outside the home. There are two rates depending on how much assistance is needed with walking and getting about.

Attendance Allowance is for people over 65. It is similar to Disability Living Allowance, but there is no mobility component. The care component has two rates: the lower for those requiring assistance during the day, the higher for those needing twenty-four hour care.

If you think that you might be entitled to financial help on the grounds of disability or low income all you have to do is claim - there is nothing to lose and all forms are normally returnable in a pre-paid envelope to the government department involved. So if in doubt, seek further advice and claim.

Anthony Gray

The rules which govern entitlement to state welfare benefits and how much claimants receive are complex. This article is intended only as a basic outline and not a comprehensive list of what is available to all.

For further information contact:

- Benefit Enquiry Line 0800 88 22 00
- www.disabilitybenefits.co.uk
- www.adviceguide.org.uk (includes contact details for your local Citizens' Advice Bureau)
- NHS Health Costs Customer Enquiry Line 0845 850 1166 www.dh.gov.uk/helpwithhealthcosts Claim form HC1 obtainable from NHS hospitals, GP surgeries etc or by telephoning 08701 555 455

There are two main types of benefits available to anyone in need. The charts show the main benefits which are available in both categories; you have probably heard of many of these. If you think you may qualify because of either low income or disablement, seek further advice from the Benefits Agency or your local council offices. Or you could contact advice agencies i.e. The Citizens' Advice Bureau or ring the telephone numbers given at the end of this article.

To qualify for a means-tested benefit your income and capital must be below a certain level. This level takes into account your needs and is based on a personal allowance for yourself and for your family members. You will need to complete a claim form. Do not be put off by the length or language of the form. Remember departments and agencies exist to help you. They are all prepared to offer advice and will even help you to fill in the forms.

Chart 1. Means-tested benefits

These are assessed on the claimant's income, capital and family composition.

Benefit	Who can claim	Where to Claim
Income Support	Unemployed people on a low income	Benefits Agency
Housing Benefit	Council or private tenants on a low income	Local Council
Council Tax Benefit	Council tax payers on a low income	Local Council
Help with NHS costs i.e. Prescription charges Dental treatment Optician's fees Travel to hospital for NHS treatment.	People on a low income	G.P. Surgery Dentist surgery Opticians NHS Hospital or Department

Chart 2. Non Means-tested benefits

These are assessed on a claimant's disability and availability for work.

Benefit	Who can Claim	Where to Claim
Job-seekers allowance	Unemployed people with sufficient National Insurance contributions	Benefits Agency
Statutory Sick Pay	Employed people with a medical certificate and sufficient National Insurance contributions.	Benefits Agency
Incapacity Benefit	Employed people after 28 weeks on Statutory Sick Pay Unemployed people with sufficient National Insurance contributions	Benefits Agency
Disability Living Allowance	People under 65 (No requirement for National Insurance contributions)	Benefits Agency
Attendance Allowance	People over 65 (No requirement for National Insurance contributions)	Benefits Agency



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Re-positioning the filter creates a modern, low-cut pouch that doesn't sag.



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I prefer a:

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My current appliance is: _____

Please note: This product is not available
with convexity at the moment.

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Address: _____

Postcode: _____

Tel No: _____

We would like to keep you informed of new products and services. Should you not wish to receive details please tick this box.

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Reader's Story...



Cynthia and her brother

Cynthia Walton wrote to tell us she has had her colostomy for 55 years. It was formed when she was twelve; seven years later she had a urostomy. She calls her two stomas "the terrible twins".

We asked her to tell us about her life...

My life has been interesting to say the least. When I was born the sphincter muscle which controls the bowel and bladder was missing. I also had a thin porous bladder and only one kidney with limited function. This caused a few problems for my parents. My first outing, at only a few weeks old, was to hospital, where doctors were also puzzled with me. There wasn't much knowledge regarding my problems over sixty years ago.

I was in and out of hospital where specialists tried various operations to mend the leaking bladder. They did a skin graft to try and patch it up. I remember it was very painful. The operation worked for about two days and I was so excited, but it was short lived and then I was back to square one.

With no control over my bladder I was always wet and had to sit on towels when I went out. My bowel muscles did not work properly either and, at the age of nine or ten, I had to have enemas every day. I remember the district nurse arriving at the house and I used to scream when she knocked on the door. As I was being sick a lot and could not go to the loo, the doctors decided I needed a colostomy to save my life. At that

time, so I am told, as a twelve year old I was the youngest person to have the operation and survive.

I was in hospital for twelve months altogether as I had to be "built up" before the operation; I was fed on chicken - a real delicacy in the 50's. My illness was more of an adult problem so I was on an adult ward. The staff were wonderful and tried to keep me occupied best they could, by giving me bandages to wrap up after they had been cleaned. Can you imagine that happening today? The nurses bought me a cloth doll with a black china head, which I called Topsy. She went to the operating theatre with me, so she had scars too, although not quite as many as I had. I still have Topsy today. Back then there was no getting out of bed after the operation so to help pass the time and to use some muscles the nurses showed me how to write with my toes!

When I left hospital after the colostomy "The Powers That Be" decided it would be better for me to go to boarding school as they didn't think I was strong enough for the "rough and tumble" of a normal school. So off I went to Malmesbury in Wiltshire about seventy miles from my home town of Birmingham. I

really didn't really want to go away again as I had spent most of my life in Queen Elizabeth Hospital. I thought my parents didn't want me at home.

The journey to the school was rather traumatic. I was only thirteen and I remember crying all the way. My father was a chauffeur so was able to borrow his boss's car to take me, my mother and elder brother on this momentous journey. Then we arrived at Burton Hill School for Seriously Crippled Girls - Yes, that really is what it was called. However, I must admit I did learn to love the place and the staff who looked after about thirty-five girls. The nurses had a job with me due to the fact that there was no information on my problems. A colostomy was rather rare in those days; no stoma equipment was available, only dressings, which were held together with what can only be described as a plastic ashtray and a sort of belt. Most of the girls were in wheelchairs. There were only about ten of us who were classed as "walkers" and we were kept busy helping the others.

Apart from a few weeks, this was the first real school I had been to. In hospital with the adults no education was provided. That would never happen today, would it? We all went

at our own pace at Burton Hill, but had to work as hard as our illness allowed. Along with a few of the other girls I was confirmed at the school by the Bishop of Bath; that was rather a grand occasion, especially as we all had new white dresses. I joined the Guides and my friend and I went to London to receive our Queen's Guide Badge. We also had a choir and would go to Devizes to sing with choirs from other schools. The competition was of quite a high standard and we usually came out of the performances very well. We all enjoyed the day out, even if we had to work very hard practising our singing beforehand.

The matron and her husband were very strict, but kept a happy school. We were only allowed visitors once a month and did not go home for the holidays, only at Christmas and in the summer. There were lovely grounds at the school with an allotment where I discovered spring onions, which I managed to "scrump". Needless to say my poor tummy was in trouble and so was I!

I was able to stay on at school an extra year to catch up with education, so I did manage to get some certificates. By the time I left there were a few stoma bags around, but made of rubber, so I smelt like a Michelin Man - not very pleasant for a young girl, a slight advantage to the dressings, but hardly Chanel No 5!

I was eighteen before I entered "THE REAL WORLD". I was sent to Pitmaston College to learn typing and shorthand, so that I could find a job sitting down in an office. I hated college: the girls were so cruel. They used to taunt me as I needed the toilet so often. I suppose the "perfume" from the bags did not help and my bladder problems were not improving. Up until then I had only been used to kind, caring people. When I was nineteen the specialists decided I should have a urostomy operation. I must admit I found this operation very traumatic. I was becoming fashion conscious and was worried about what sort of clothes I would be able to wear - getting my priorities right wasn't it? I was also rather fed up of hospital life. It took me a long time to recover from the extra stoma and to manage my 'terrible twins' as they are now called. There was no help when I got home: no specialist nurses as stomas were still something of a rarity.



Cynthia with her granddaughter, Leanne, her grandson, Ashley, and her son, Steven, who is holding her great grandson, Jamie.

The equipment had improved somewhat, but there was nowhere near the choice we have today. I just got on with life the best I could. I was still living at home so did have my parents "on hand" if needed, although my mother was not the nursing kind. She never had much patience with me, as she always wanted a "proper little girl" who could be dressed up, which I never could. My Dad was wonderful and so was my maternal grandmother, but she died when I was quite young. Once I got used to the extra stoma I managed to keep a lot drier, even if the bags did come off a lot more than they do today.

When I was twenty-five I married the brother of a friend who lived up the road. We had known each other since childhood and he was so understanding and very good to me. As I could not have children my husband agreed that we should foster babies who were waiting to be adopted. I loved that. There was a problem finding a permanent home for one of the babies, so we applied to adopt him. Our application succeeded, so the baby I had cared for from ten days old became my son. He is now forty-one and has three children, so I have been very lucky in that respect.

Sadly in 1974 my husband died of cancer. I nursed him at home. We had only been married for ten years; it was devastating as he was my rock. Luckily I have been very fortunate with some wonderful friends who have helped me out. They would take my son on holiday or invite him to stay over when I had to go back into hospital for more operations and treatments. I have had fifty-six operations up to now, but do not intend to add to that number. There wasn't counselling in those days so we just got on with life as best we could. I think coping with the difficulties of life makes you a stronger person.

I am so grateful for all the help we get now. I still do not have a stoma nurse but I know I can always phone up the company that supplies my appliances and there are so many more associations about to help us out. The equipment today is wonderful: so much choice and information to help us on our way.

I count my blessings and feel lucky that I have managed to survive for so long. I try to make the most of each day with a smile.

Cynthia Walton



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

Dear Nurse...



Q: I am trying to find some information on colostomy reversals: how they are done and how long a patient can expect to have to stay in hospital. My Mother is sixty-seven years old and has a temporary colostomy. The doctors have told her that after a few months they will reverse it. My parents are very apprehensive about this because we almost lost her when she had the first surgery. The doctors say they will discuss what the operation involves nearer the time. However, we would like some detailed information now, so they can sit easy and know what to expect. Can you help us with this?

A: You can meet with your local stoma care nurse to discuss the reversal operation in more detail. She will be able to explain exactly what the surgery will involve which I am unable to do as you do not say if your mum had an end or a loop colostomy. If she had a loop colostomy then the surgeons will not need to open the abdominal wound again. However, if it is an end stoma the abdominal wound will need to be opened again. Obviously length of stay will depend on which surgical approach is used; if the abdomen is opened then length of stay is likely to be longer. There are risks involved with any surgery and again the local stoma care nurse will have access to your mother's previous history and therefore will be able to discuss the risks in more detail. It may also be possible for the stoma care nurse to provide your mum with written information and even a visit from a patient who has undergone a reversal procedure.

Q: I have been a wheelchair paraplegic since 1970 and my colostomy was formed in 2003. My stoma is exceptionally well behaved, but I have a small parastomal hernia. As I have no sensation below my naval and no muscle control whatsoever, everything sags and I feel I need some form of support.

My question is this: How does one know whether a hole to accommodate the stoma, is required or not? The support garment manufacturers offer to make one so the bag is worn outside the garment. Does this hole not cause the stoma to protrude and become prolapsed? On the other hand if there is no hole and the bag is worn underneath, do these support garments allow the contents of the colon to flow out into the bag?

What I want to know is what does the "average" colostomate choose? Which is the support garment or belt most people prefer? Which is the one most recommended by the experts?

A: There are differing opinions with regard to the hole in abdominal support belts. Some patients choose not to have a hole in the support garment to start with, choosing to alter the belt themselves if they then find there is a problem with 'pancaking' due to the pressure from the support. Other patients choose to have a hole put in it immediately. Some manufacturers of abdominal supports say that by putting a hole in the belt the amount of support immediately around the stoma is reduced. Personally I find that most of my patients choose not to have the hole put in when they are fitted. As for which support belt is preferred this is dependent on the size of the parastomal hernia and how much support is required. This decision is made following a review by your local stoma care nurse.

Q: Three weeks ago I underwent a Hartmann's reversal & hernia repair. Following surgery I used a self administered pump for pain control for three days. It was reasonably OK when lying down and with a catheter in place, but any movement was genuinely painful. When the pump and catheter were removed I was given two doses of Oramorph and was in extreme pain on moving and even when just lying down. The follow up pain relief was soluble Paracetamol and Codeine, which did not make any improvement but staff seemed reluctant to give me anything else.

I was discharged on the sixth day. The staff were aware that my pain levels were still high but I was assured it was "early days" and would get better. The day after my discharge I had to contact my local surgery for pain relief and they supplied Tramadol, Movicol and suppositories, none of which was suggested by the hospital.

Two weeks after discharge I had a follow up appointment with my consultant and was prescribed Tramadol Hydrochloride and Diclofenac Sodium tabs. This has eased the really raw pain. I now have a persistent dull deep aching pain in my left hip and across to the central spine and back passage. The stoma/hernia area is sore with the internal stitches, which of course I expected. At the end of the day my stomach on both sides is incredibly tender, and I long for some good sleep.

Was this experience due to lack of preparation and information or is it usual or just pure bad luck? I have had two Caesarian sections (the first baby was 11lb. 2oz., the second 9 lb.) and emergency surgery for a perforated bowel/peritonitis so would not consider myself a delicate little flower. I am quite tough but the pain of the last three weeks has been exceptional.

What would you advise regarding exercises at this stage? Also any tips on general well being would be greatly appreciated as I seem to be very "Tired and Emotional" right now.

Sorry to bore you with all of this, but my previous contact with you was so helpful.

A: I am sorry you seem to have experienced such a lot of pain following your reversal and hernia repair. Some pain and soreness following this type of surgery can be expected. However, it would be hoped that this can be controlled to an acceptable level with careful assessment and monitoring of pain levels and treatment. It will take quite a while to recover from this surgery. As you are only three weeks post-operative I would expect you to have some tenderness at the site of the surgery but hopefully the severe pain can be controlled with appropriate pain relief. If the pain relief you are currently using is not managing to control the pain it may be worth a review from either your GP or consultant surgeon to assess if there is anything else that would be more appropriate.

Following this sort of surgery I would suggest no lifting or abdominal exercises for

Dear Nurse...



eight to twelve weeks and then to gradually increase the amount of lifting/exercise that you do. If you do a lot of lifting it may be worth a review with your stoma care nurse with regard to using an abdominal support.

Q: *I have only recently received my colostomy and am trying to learn to live with it.*

My problem is leakage from the bag. The faeces forces the bag away from my skin and I am left with a terrible mess. Sometimes it happens during the day and now more regularly at night.

I always make sure that the bag is firmly attached to my skin, no bubbles of air that could lift it away, and yet within a short time the bag is lifted off by the mess coming out of the side. My stoma nurse has ensured that the hole is the correct size for the stoma, taught me how to ensure the skin is free from perspiration and oils and I make sure that using the warmth of my hand and fingers, seals the bag to my skin – and yet I still have these distressing accidents.

I would appreciate all help and advice.

A: You do not say what your output is like. If it is quite formed but 'sticky' you may be suffering from 'pancaking' whereby the stool does not drop into the bottom of the pouch but sits at the top. Eventually the motion will push the pouch away from the skin causing a leakage. Altering your diet can make the stool more formed or looser allowing the motion to drop into the pouch better. Foods such as bread, pasta and rice can thicken the stool and foods such as citrus fruit, green vegetables and fruit juice will make it looser, but it is always best to experiment with different foodstuffs as everyone is an individual and foods can affect people differently. Alternatively you could use a filter cover on the air filter to allow a cushion of air to remain in the pouch allowing the motion room to drop into the bottom of the pouch. You could also try using a lubricating gel or a sponge cube to prevent the 'pancaking'. Both these can be obtained on prescription and details are available from your stoma care nurse.

Q: *I have written to you before, last summer, about a problem I have with staples coming up under the skin around my stoma. As you know I had a colostomy after I was*

burnt from the waist down in the Kings Cross fire. I had a urostomy formed in 1992, then a reconstruction in 2002 but I was left with an incisional hernia, which has been repaired a number of times.

I had an operation in April 2005 for repair of a hiatus hernia and fundoplication, then another in September 2005 for repair of an incisional hernia and re-siting of my colostomy to the other side.

Since then my stoma is very painful and I have this problem with staples coming up under my skin. I have to leave the pouch off due to the pain. I asked my GP to refer me to another consultant at another hospital, but this was taking too long so I went to the emergency department. An X-ray showed up all the staples in my body - there are twenty-nine around my stoma.

They have told me that they will have to re-site my stoma again and have put me on the waiting list. I will have to wait up to 6 months. I did not want another operation as I have already had sixty-four since my trauma in the Kings Cross fire. I am now 54 years old. What can I do to speed up this operation? These metal staples are so small and cause such problems, why do they use them on patients?

A: I am sorry you are traumatised by your experiences, both from the fire and the consequences of the surgery you have had. It may be worth speaking to the stoma care nurse or the consultant surgeon again regarding your fears and the worsening problems with pain around the stoma. They may be able to help you with regard to the timing of the surgery, especially as there may be a clinical reason for performing the surgery earlier. I am unsure what these staples would be used for and why they are causing so much trouble as I do not have access to your surgical records. Again you would need to speak to the consultant who performed the surgery using these staples. He would be able to explain in detail what they were positioned for.

Q: *I shall be interested in the article on sexual dysfunction in a future issue of Tidings. In Nov 97 at the age of seventy I had an abdomino-perineal resection for carcinoma of the rectum. The operation, after radio and chemotherapy, was a success and I have never had any major problems. I use a closed bag and in my travels all over the western world have managed very well.*

The point I would like to make is this: after my colostomy operation I lost all my sexual functions. In addition to being unable to achieve an erection I lost sexual feelings completely. My doctor suggested Viagra but my wife and I decided that, at our ages, it was not worth the trouble. We have had ten years of living without sex and are now adjusted to it. Was the trouble caused by the surgeon cutting a vital nerve, and could this have been reversed. Your comments would be appreciated.

A: Sexual dysfunction is an acknowledged potential problem following surgery in the pelvis such as the abdominal perineal resection you underwent. The problem is often due to damage to the nerves which is often unavoidable. Patients should be made aware that this is a potential problem post-operatively during the counselling prior to surgery and be offered review post-operatively to assess the degree of sexual dysfunction for the individual. Viagra is just one treatment available on the NHS for this problem but a review by a specialist is required to identify the most appropriate treatment for the individual.



Dear Nurse...

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

Colostomy Association,
15, Station Road,
Reading RG1 1LG

or e-mail
cass@colostomyassociation.org.uk

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



A Day in the Life of Julie Rust

Julie has been our stoma nurse columnist answering Tidings readers' questions on the "Dear Nurse" page for over two years. Working Mum, Julie, entered stoma care in 1990 and became a clinical nurse specialist in 1998. She now runs a forward-looking stoma care team that provides comprehensive care to more than two hundred patients a year. Back in 1999 Julie along with Val Moss (now retired), Lee Findler SCN and myself formed the North Staffs Ostomy Support Group, "Outlook", a group that works closely with the nursing teams, successfully providing pre and post-operative "psychological" care in the hospital and the home. We are now considered part of the "hospital team" not only by the specialist nurses, but also by surgeons themselves. One of the eminent surgeons referred to the support group members as being the "True Experts".

I asked Julie to give us a brief insight into one of her working days at the busy Bowel Care Department at the University Hospital, North Staffordshire.

Ernie Hulme



Julie Rust & our Trustee, Ernie Hulme, at a meeting of Outlook the North Staffs Ostomy Support Group.

Julie's Day

It's 7am yet again and time to get myself ready for another day at "the office". My day usually starts off manic and generally stays that way until bedtime. Still it keeps me out of trouble!

If I'm lucky it's a day when my husband, Steve, who is a Community Paramedic Officer with Staffordshire Ambulance Service, is home to help get everyone ready, otherwise I'm on my own! I wake our two daughters, Megan age 9 and Caitlin age 7 and get them ready for school then sort our two Staffordshire Bull Terriers, Reggie and Roni. Once everyone is fed and watered I walk the girls to school and then return home to drive to work, hopefully arriving at approximately 9.15am.

My first job at work is to check the diary for the day's work which includes visiting all in-patients in our busy acute Trust during the morning and running a Nurse Led Clinic in the afternoon. Also today I need to assess the ward work and the home visits for next week to allocate them to the appropriate staff.

Once this is done my next job is to complete the work generated from a busy Consultant Led Clinic on the previous day. We have three dedicated colorectal surgeons and four dedicated urology surgeons within our Trust so our workload can be quite large, with approximately two

hundred new stomas being formed each year. We also care for patients undergoing colorectal surgery for cancer who do not have a stoma, so this also impacts on our caseload. We find the best way to support patients is to follow them throughout their complete journey, starting in the Consultant Led Clinics where they are given their diagnosis and treatment plan. After this appointment a home visit from myself or another nurse specialist is arranged to discuss the diagnosis and surgery in greater detail and provide written and verbal information. It is often at this point that we involve our patient visitors, of which we have a very dedicated group, both with and without stomas. This offers a good support network for our new patients and allows them to have direct contact with the true experts, those patients who have already travelled this journey.

Later I join my two specialist support nurses on the wards to support and teach patients with newly formed stomas. This work is an important part of our role and includes ensuring patients are well prepared for surgery and are supported following surgery. We also use this time to help the ward staff to deal with difficult stoma and wound problems and to provide training and support for all grades of staff, including student nurses and medical students.

Now it is time to grab a quick sandwich, which we eat during our lunchtime departmental meeting, where we are able to discuss any problems we have encountered during the morning and the progress of all our patients. The aim of this is to support each other and to ensure that all our patients are receiving the most appropriate care, both in the use of products and in the preparation for discharge. We also check our answer-phone for messages which we must answer before we leave for the clinic. These can be from wards we do not visit regularly or from patients who require support or booking into our clinics, who are worried regarding their follow-up appointments with Consultants or who are waiting for tests or results. This is a very important part of our role and can help to prevent problems occurring or worsening for patients.

Next it is on to the Nurse Led Stoma Care Clinic, where we see up to sixteen patients for both routine stoma follow-up and for problems

related to their stoma. This afternoon we have a quiet clinic with only twelve patients to be seen. Although we never know how long we will need to spend with each patient, we try to keep to our allocated time-slots but as you can imagine if a patient needs lots of support this can sometimes be impossible and the clinic can over-run! This afternoon is not too bad with four follow-ups, where we check the individual is managing their stoma without any problems, is eating and drinking well, has no surgical/wound problems and is using the product they are happiest with. It is here we show our assortment of all other appropriate products and order samples for the patients to try if they wish. If everything is okay we will next see the patient with the consultant surgeon or oncologist in the Out Patient Department. However, if there are problems or concerns, we may arrange to review the patient again in the Nurse Led Clinic. The reasons patients attend the clinic range from girdle fitting for abdominal support for parastomal herniation, problems with sore skin or product leakage, to advise on travel, employment or personal relationship and general support. Some issues can be quite complicated and need review by ourselves over several appointments or, if we feel it is necessary, referral to other agencies.

Finally once all the paperwork is completed and all jobs - from the radio-pages we have been getting throughout the day to solve any problems on the wards or from out-patients needing advice over the telephone - are up-to-date, we are able to shut-up-shop and go home.

I may have finished my paid work but now the unpaid part starts! Firstly if my husband has not already done it I need to fetch my children from the after-school club and then it's home to feed the five thousand (or so it seems!!), walk the dogs and get my husband off to work on a night shift. Once everyone is dispatched to where they need to be and the housework is completed, it's finally time to sit down for a well deserved (well I think so!) glass of wine!



Not a lot of people know this but...

Q. When I was little I wanted to be...

I always had links with the local hospital as my dad was an "ambulance man" and my mum worked in the local A&E department (called Casualty then!) so I always wanted to be a nurse!

Q. If I could be somebody else - I would be...

I don't think I would be anyone else. I'm happy with my lot. I have a fantastic husband, two lovely girls and a job I enjoy doing as so many patients remain 'friends' for years to come.

Q. When I have time to myself, I like to...

sit and relax with a good book.

Q. My biggest weakness is...

my girls. I will do anything for them.

Q. My greatest strength is...

my organisation skills (at least I think so, although Steve probably says it's "nagging"!).

Q. After a bad day at work and I am feeling down I...

go home for a cuddle from my husband or girls and a big sloppy "kiss" from Reggie and Roni our two Staffordshire Bull Terriers.

Q. The place I love the most is...

anywhere with my family.

Q. My proudest moment was...

I have three special moments in my life. Marrying Steve my husband and giving birth to my daughters, Megan (9) and Caitlin (7).

Q. My favourite meal is...

anything romantic with my husband as we don't often get time to spend together as a couple. We are both so busy with the children and work - we often don't see each other for quality time together due to Steve's shift pattern as a Paramedic Officer.

Q. The shop I always look in is...

Next, especially the childrens' section, as I am a sucker for spending money on nice clothes for the girls.

Q. My ideal weekend away is...

camping with the family and dogs. I find it so relaxing away from everything - and no cleaning the house either!

Q. I use the Internet mainly for...

research for work. I have just finished my Masters Degree so I seemed to live on the Internet recently!

Congratulations on being awarded an MSc, Julie, from everyone at the Colostomy Association

I did it! I sang with the choir in Carnegie Hall

Celia Patten wrote to tell us of her trip to New York to take part in the Martin Luther King Remembrance Day Concert at Carnegie Hall.



I was taken seriously ill in the middle of July last year when my bowel burst and caused severe peritonitis. On three occasions I was close to losing my life with organ failure and I ended up with a colostomy. I was not discharged from hospital until the middle of September and was, by then, in a very debilitated state. It was the closeness of my family and friends and also the prospect of going to New York to sing in Carnegie Hall with my colleagues that gave me a target for my recovery.

I sing alto with the Billingshurst Choral Society; our musical director is George Jones. Together with his other choral society, Angmering Choral, an Irish choir and one from Kentucky we were invited to sing Karl Jenkins's music, *The Armed Man*, *Mass for Peace*. There were 180 members and followers that were to make the journey from London to New York. I was very apprehensive about the journey and how I would cope with my stoma and being "on stage" for over an hour.

As someone who has to walk with sticks I was concerned about check-in at the airport. However, I was lucky and received assisted passage which meant that I was placed in a wheelchair and pushed through the queue as a priority customer. I (and others who were in the same position) were found seats before check-in, and then seated in the aircraft before the other passengers.

I was concerned that my stoma might work during this time so I had been very careful with my diet and taken jelly babies to slow down the output. I wore a drainable bag to travel and during the flight my bag filled with air but easing the pouch a little released the air. I had no problems with the

journey with regard to using the toilet but I was stopped by security! The metal rod on my hand/wrist, because of carpal tunnel syndrome, triggered the security alert. The security officer was very good, while apologising that he had to run the security check on me. He wanted to unpack my cabin bag. I requested that this be done in a private room away from the eyes of the other passengers and he agreed. Arrival in New York presented few problems, as again I was fast-tracked in a wheelchair through the checks to the luggage reclaim.

We stayed at the Grand Hyatt Hotel in New York and though the rooms were adequate there was no closed disposal bin in the bathroom. I had made a conscious decision to carry a number of plastic carrier bags - so I was able to rinse through my used bag, enclose it in a disposal bag and then wrap it up well in the extra plastic bag. I did ask at reception for a bathroom bin, saying I had a colostomy. I was faced with 'I don't know what you are talking about' and had to explain. However, the bin still did not materialise.

I was able to do a limited amount of sightseeing. Out and about in New York, I found everyone most helpful and considerate with my disabilities and disabled facilities are great. However, public toilets seemed to be very scarce. They are mainly found in restaurants and shopping malls. Grand Central Station was an ideal place to eat and provided good facilities in a pleasant atmosphere.

Rehearsals were held in the ballrooms of the hotel. The Martin Luther King Remembrance day concert was in Carnegie Hall. Those of us in wheel

chairs were invited to be in the front row on perch stools. I needn't have worried about being on-stage for an hour or more. I was fine. The musical experience both in the practice sessions and finally the performance was wonderful and left me with quite an adrenalin surge.

There were 250 choristers on stage and relatives and supporters in the audience. Karl Jenkins had come over with us; it was to be the first performance of his music in America. We sang the mass in the second half of the concert and were given a standing ovation, which felt incredible. The Musical Director was Jonathan Griffith, a very prominent conductor in America. He was wonderful and shook hands with every one of us as we left the stage.

After the concert, together with our supporters, we were then taken by coach to New York harbour for a late night cruise to the Statue of Liberty and on the way back to the hotel a hot supper with wine was provided.

On the return flight everything was fine - again with assisted check-in. My bag needed changing but this was well managed in the tiny cubicle. I ensured that the used bag was well wrapped in the plastic bags and disposed of in the disposal chute.

So take heart any new members of the Colostomy Association who may have misgivings about flying. It can be done easily.

Celia Patten

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A Reader's Reply...

The letter from Julie in the Spring edition of Tidings was a breath of fresh air. How inspiring it was to read about someone taking on the challenges of life with a colostomy in such a positive way – one that reflects the realities of her life as it really is rather than bowing down to the pressures of others who probably have little understanding of what life with a stoma actually entails.

I, too, had a prolapsed rectum that first became apparent when I was twelve and was finally repaired at the age of twenty-eight with a rectoplasty; two previous operations to insert silicone bands having failed to remedy the problem. However, I continued to experience severe constipation and nausea and five years later, in 1992, I had a colostomy, which I have to say brought a vast improvement to my quality of life for the simple reason that I no longer had to spend several hours a day on the loo. However, I still continued to experience nausea, vomiting and stomach pain and in 1994 I was diagnosed with pseudo-obstruction, a condition in which there is a failure of the propulsion of food through the intestine due to various abnormalities in the muscles or nerves of the intestinal wall.

For the next eleven years I continued to try to cope with the challenging symptoms caused by food effectively obstructing my bowel, but by 2005 my quality of life was so poor that a decision was made to start feeding me intravenously. This treatment is called parenteral nutrition and refers to nutrition that is given directly into a main vein close to the heart via a catheter, or a "central line". Each patient's nutritional requirements are assessed individually and in my case this meant infusing two litres of fluid over a period of approximately eleven hours, five nights a week, and I'm happy to say that now I no longer have to rely on eating "normal" food to remain nutritionally well, I do feel much better.

However, like Julie, I find that one of the biggest obstacles I come up against isn't the intravenous feeding itself, or dealing with my colostomy, but having to adjust to everyone else's expectations of these treatments. For me, these medical interventions are just part of a treatment regime for an ongoing medical condition, the effects of which I still have to deal with every day. Parenteral nutrition has remedied the malnutrition caused by the effects of long term nausea and vomiting, and my colostomy has enabled my bowel to at least function in some sense of the word, but I still have to live with the same set of symptoms on a daily basis. My gut still does not work efficiently and never will, and this is a hard concept for others

to grasp, especially given the surgery I have undergone and the fact that I now rely on intravenous feeding five nights a week.

People assume that undergoing such complex treatment and surgery automatically means that I am "cured", and with regard to my colostomy and bowel condition in particular I am constantly being given well-meaning advice from others about what I should be able to achieve. The type of advice that I find really irritating usually comes from people who not only don't have a stoma, but have never suffered from any bowel disorder in their lives, yet nevertheless think they are experienced enough in this field to tell me how they would "manage" with my symptoms if they were in my position. Such advice usually consists of such staggeringly pointless tips as scheduling 'rest periods' during the day, or 'lying down for half an hour' as a means of managing gastro-intestinal symptoms whilst on holiday. As anyone with a bowel condition knows, "taking a nap" for half an hour will not cure the nausea, vomiting and abdominal pain caused by an obstructed gut, or any other bowel disorder.

I'm not one for naming my stoma and for me this is a good thing. It reflects the fact that I see my stoma as a normal, much valued, part of my body. I've accepted it and treat it with the same respect as I would those body parts I was born with – after all, I wouldn't dream of naming my legs or ears. However, I did find the letter in the Spring edition of Tidings from the person who had named her stoma 'Grace' very touching and I share her sentiments. Having spent my teens and twenties coping with the indignities of an embarrassing bowel condition, having my colostomy at the age of thirty-three did at last bring some grace back into my life.

Since having my colostomy I have received a great deal of support from the Colostomy Association and it has been very encouraging to read of other people's experiences in each edition of Tidings. In addition, I have also received much valued support from another patient organisation called PINNT, a registered charity which supports both adults and children who require artificial nutrition of any kind, including parenteral nutrition (given directly into a vein) and enteral nutrition which refers to nutrition that is given via fine tubes placed in various parts of the digestive system such as down the nose (nasogastric), directly into the stomach (gastrostomy feeding) or directly into the small bowel (jejunostomy feeding). PINNT produces literature on many aspects of artificial nutrition and also publishes a

"Holiday Guidelines" booklet, free to members. This covers everything from finding appropriate insurance cover for patients with medical conditions, to taking medical supplies abroad. PINNT also publishes a quarterly magazine for members and offers full support to both patients on artificial nutrition and their families and carers.



The combination of my colostomy and the intravenous feeding have enabled me to feel well enough to really appreciate the everyday things in life and, like Julie, I don't need to swim the Channel or navigate the desert on a camel to feel that I

am getting the most out of my life. It's being able to do the little things that matter to me. And, when it comes down to it, the little things are really the big things – the things that we all remember when we look back over our lives: being there when my children came home from school and being well enough to just sit and talk about what their day had been like, studying my daughter's university textbooks with her and having a lively debate about the things that are important to her, having the energy to spend an afternoon "girlie" shopping with my daughter and trying on clothes that are far too fashionable for a forty-eight year old – but doing it anyway.

Many people spend their whole year putting all their efforts and hopes into planning for their two weeks in the sun, but I believe that the essence of a really good life is to make the most of those little things that happen every day and can all so easily pass us by whilst we're planning for the "big stuff": building that snowman by torchlight in the dark because the snow might have melted by morning, taking a walk by the river with my husband, reading a book on a sunny afternoon or cold wintry evening. It doesn't matter whether you're a mountaineer, a trekker or someone who prefers to stay closer to home. At the end of the day, all that really matters is that you are content with what you do.

Barbara

For more information about PINNT, please write to PINNT, PO Box 3126, Christchurch, Dorset, BH23 2XS, or email: PINNT@dial.pipex.com, or telephone Carolyn Wheatley on 01202 481625.

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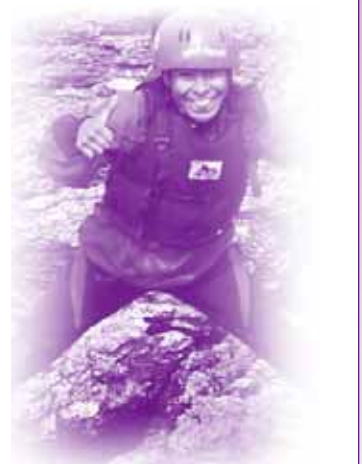
Various Ladies Styles



- Stop Press • Stop Press • Stop Press •
- Stop Press • Stop Press • Stop Press •
- Stop Press • Stop Press • Stop Press •

The organisers of "Breakaway Weekend" have recently announced that some sponsored places are available at their adventure holiday to be held on 17th-19th August 2007 at YHA, Bryn Gwynant, Snowdonia. (See P.13)

If you are between the ages of six and eighteen, have a stoma and would like to attend, but cannot afford the cost of the accommodation and activities contact Rachel on 0775 1560013 who may be able to help.



Hypnotherapy for Ostomates

Following stoma surgery, many people have serious and on going problems with their body image. They may feel unattractive or even ashamed of their bodies. This can have repercussions on their social life and personal relationships.

Hypnotherapy is an aid for anyone having difficulty adjusting to life with any form of stoma. Hypnotherapy can help people come to terms with their new body image, how their body now looks and functions and can repair dented self-esteem and confidence, also turn acceptance of a stoma into appreciation. For some people a stoma is a life-changing event for the better, bringing better health and a brighter future. However, for many people diagnosed with cancer a stoma is an unexpected life saving procedure. Hypnotherapy can be used to prepare psychologically for surgery; this in turn would be beneficial for post-operative recovery as the formation of a stoma would have already have been accepted by the subconscious mind.

How does hypnosis work? The brain has a conscious, logical thinking part that we use to make choices such as what clothes to wear, what newspaper to buy. It also has the unconscious part that is responsible for the way our bodies function and the way our minds work. This is the part of the mind that we target with hypnotherapy. By using relaxation techniques and carefully worded suggestions it is possible to change how we feel about ourselves both physically and psychologically. And when we feel good about ourselves we are more confident and contented in all areas of our lives; this is beneficial for ostomates of all ages and backgrounds.

For people contemplating whether surgery is the right way forward for them, the subconscious mind is a useful tool and is able to help inform their decision. Using hypnotherapy, it is possible to access the subconscious mind and ask for guidance from your deeper self. The subconscious mind is responsible for all our automatic functions, like regulating our breathing, balance, even blinking our eyes; all this happens automatically because the subconscious mind knows what our bodies need and when these needs should be met.

Another well-documented benefit of hypnosis is pain control. Using hypnotherapy, alongside modern medicine, to control pain has many advantages. Hypnotherapy has no side effects and with training can be self-administered regularly.

So how does this work? First we need to ask, 'What is pain?' Pain is a signal sent from damaged or inflamed nerve endings to inform us that all is not well in a specific area of the body – that this area needs our attention. Signals are sent through the nervous system up into the brain where they are interpreted as different types of pain i.e. sharp, throbbing or a red hot burning sensation. With careful use of hypnosis it is possible to dull sharp pain, sooth throbbing pain and cool any hot burning sensations by using suggestions whilst in hypnosis. Another option is to visualise the pain as an image with colour, texture, even with sound and temperature and maybe a name. By changing the colour, texture etc. of this image the pain changes too, becoming a more comfortable awareness of the sensation.

Most people can subconsciously substitute a different time to experience the pain. This can be spontaneous; you may have heard people say something like: 'I don't have time for this headache right now.' You have probably done this yourself at some time only to discover later that the headache has dissipated. Athletes who injure themselves in competition often don't realise they have an injury until the event is over. These are common every day episodes of substituting a different time and place to experience. As this can be done spontaneously it is possible to learn how to do it deliberately.

Most good hypnotherapists should be able to help. However, I would recommend a member of the British Institute of Hypnotherapy. As a fellow ostomate I am uniquely qualified to be able to help most people with a stoma.

David Joy MBIH, Master Practitioner of Hypnotherapy and registered IBS therapist
www.davejoyhypnotherapy.co.uk

The British Institute of Hypnotherapy, 12 Heycroft Road, Eastwood, Essex, SS9 5SW
Tel: 01702 524484,
www.britishinstituteofhypnotherapy.org
can provide contact details for David Joy or another hypnotherapist with a practice in your area.

Before seeking advice from a hypnotherapist, it is important to report any new symptoms e.g. pain to your consultant, GP or stoma care nurse, who will be able to arrange investigations to rule out an underlying physical cause.

Reader to Reader...

Dear Tidings

I am seventy-five years old and live alone in a bungalow with a small garden in Hastings. I have had a colostomy since 1980 when I nearly lost my life during the operation. I cannot have it reversed unless I am in pain, as more surgery will be risky. I had a mild stroke in 1996 and, outdoors, I walk with a stick.

My interests are gardening, wildlife, travel, television and reading. I would like to meet someone else who has colostomy, either male or female, for friendship, an understanding person who knows what it's like to live with a stoma.

Hope you can help.
Yours
Robert

If you would like to contact Robert write to Head Office and we will pass on your letter.

Dear CA

I am healthy, honest, active, ex-public school, living alone in the North Berks countryside since my divorce some twelve years ago. I have three adult, married children and four granddaughters. I am a retired cereal farmer and my land is rented to a neighbour. As a hobby I like repairing broken or neglected articles. I also enjoy travel both on land and sea.

I would very much like to find a lady companion, who has no qualms about a colostomy, to possibly cruise and travel with me. We colostomists are somewhat lepers in the social world, but two of a kind would understand and help each other to cope. I am able to do most things as easily as I did before my operation, four years ago, and have learned to live a comfortably normal life, as good and happy as everyone else of the same age.

Yours sincerely

Bob

If you would like to contact Bob write to Head Office and we will pass on your letter.

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*Ethik, Journal of Nursing, 26 January 2007



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Mid Essex Stoma Support



There's always time for a cup of tea and a chat.



Members enjoying a buffet lunch on the day trip to Rochester.



The Annual Christmas dinner.

On 11th October 2002 Stoma Care Nurse Nikki Saunders arranged a meeting at Broomfield Hospital, Chelmsford to gauge the interest in forming a local support group for all ostomates within the Mid-Essex Health Authority. Sixty-three people attended - thirty-seven ostomates and twenty-six partners and friends.

And so the Mid Essex Stoma Support Group was born.

A committee of four was elected comprising Chair, Secretary, Treasurer and Nurse Representative and the Rules and Constitution formulated. The group's aims were agreed:

- give patients/ostomates the opportunity to meet and talk informally with others who have a stoma
- get together on a social basis at meetings and other specially arranged events
- keep everyone updated regarding the latest ostomy products and services.

Almost five years on, we have 120 ostomate members. Ostomates' partners and friends are important to us and we have therefore welcomed them as members too, swelling our numbers by a further 75 to an overall total of 195.

A typical edition of our popular quarterly newsletter, *The Messenger*, will include a review of the most recent, and news of forthcoming, social events. There will also be a page or two devoted to Hints 'n Tips, an update regarding membership numbers, members' news and letters and invariably a competition. Ostomy manufacturers may place a small advert in return for a donation to the group's funds. Photographs are an important aspect of the newsletter, giving it a much more personal perspective for a small and local group.

Formal meetings take place in March with our AGM, and September when a guest speaker is invited to talk about a subject we feel will hold members' interest. Our social calendar focuses

much more on events which provide people with the opportunity to chat. Evening meals and get-togethers have been the norm with coach trips in the past to Rochester, Windsor, Hampton Court, Southwold, Duxford, Eastbourne and Leeds Castle.

Our 2007 programme is typical of the last four years, with an event roughly every six weeks. We held a Ploughmans Supper in February, AGM in March and enjoyed a trip to Rochester in May. On June 23rd we have a coach trip to Canterbury and on August 4th a trip to Hastings; the destination of our trip on September 15th is yet to be determined so it could even be a mystery tour! Moving into the autumn, we are delighted to celebrate our 5th Anniversary on Sunday 14th October with a special buffet lunch, with our Annual Quiz Night on November 23rd and Annual Christmas Dinner on 14th December.

Group funds are usually retained for the benefit of members. However, in 2006 and following a year of particular generosity of members, their families and friends we were delighted to donate £250 to each of two Broomfield Hospital appeals - the Capsule Endoscopy Appeal and Urology Research Fund.

Members say they enjoy our group and it's special to them because it's small and intimate, creating the right environment for members to see and chat discreetly with others regularly about anything and everything - stoma-related or otherwise. They say they don't want that to change - so it won't!

For further information about the Mid Essex Stoma Support Group contact Clive Blanchard 01245 468750 or clive.blanchard1@btinternet.com

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.

News of local stoma support groups

"The Monday Pop In Group" meets every Monday from 2pm until 3.45pm at Martin's Heron Community Centre (in Tesco car park), Bracknell, Berkshire. For further information contact Jackie Dudley 01344 426652

"Bags of Support" meets on the last Saturday of the month from 10 am until 12 noon in the Ante Natal Department at Frimley Park Hospital, Portsmouth Road, Frimley, Surrey. The next meeting will be on July 28th. For further information contact Beryl Goddard 01252-835364

The next meetings of **The Swansea Ostomy Self Help Group** will be on Monday 9th July and Monday 10th September. Both meetings will be held at St Pauls Parish Centre, De La Beche Road, Sketty from 2pm until 4pm. For further information contact Glynis Jenkins 01792 418245

In the **Newcastle area** there are two support groups. They meet: every week on a Friday from 10am until 12noon at Arthurs Hill Clinic, Douglas Terrace, Newcastle-Upon-Tyne. every other month from 10am-12noon in the Bewick Seminar Room, Leazes Wing, at the Royal Victoria Infirmary, Newcastle-Upon-Tyne. The next meeting will be on 25th July 2007.

If you contact us before 20th August we will publish the date and venue of your next Stoma Support Group meeting.

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

Department of Health & Scottish Executive Updates



Department of Health

The closing date for responses to three consultations, about the provision of stoma care appliances was the 2nd April. The Colostomy Association submitted responses along with the other patient organisations, manufacturing and supply companies and various nursing organisations. A large number of responses were also submitted by individuals although it has not yet been possible to identify exact numbers. The original plan was to have a summary of these responses available on the Department of Health (DoH) website by the end of April.

On 23rd May The Department of Health made the following announcement.

"The volume and complexity of the responses are such that the Department has decided that it needs more time to analyse the information provided. Consequently, no changes will be implemented in July 2007 as previously proposed. The needs of patients are paramount and the Department is committed to ensuring that their care is maintained and, where appropriate,

improved. The Department seeks to ensure that the NHS is receiving value for money and want to make sure that the services provided by all dispensing contractors are to the same standard no matter where in England a user of these appliances may live. At this stage, I cannot tell you when we will have completed the overall review, but I do not anticipate that it will be before the end of the year. Please be assured that we will keep you updated as and when necessary."

To keep abreast of developments visit the 'News' section of our website. www.colostomyassociation.org.uk

Scottish Executive

Due to the recent elections in Scotland, the regular meetings with the Scottish Executive to discuss the impact of recent changes in stoma care have been put on hold until September.

To enable us to provide feedback to the Scottish Executive about the service that our members have received since the changes in 2006, we included a brief questionnaire for our Scottish members in

the Spring issue of Tidings. We received in excess of 230 responses and it was pleasing to see the high 'satisfaction' scores that resulted. In summary the key results were :-

We asked our members to rate the service that they received on a scale of 1 to 5 with a score of 1 being very poor and a score of 5 being very good.

91% rated the service provided as good or very good
97% rated the delivery service as good or very good
98% rated the packaging as good or very good
97% rated the overall 'end to end' service as good or very good

May I thank all our members who took the time to complete and return the questionnaire. We will be discussing these findings at our next meeting with the Scottish Executive.

Ray Goddard
Managing Trustee

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Readers' Writes



I know it will probably be in three or four months time, I am getting very anxious as to whether I am doing the right thing. I have heard there is a fairly high failure rate and that recovery is more difficult and traumatic than the original colostomy operation. Could you please tell me if this is true and how past colostomates who have had this operation now feel about their experiences.

Yours Faithfully
R.C.

We were already planning to include a feature on reversal in an issue of Tidings later this year. In view of the number of letters we have received recently on this topic we are now hoping that we will be able to get a medical professional to write an article for the Autumn issue. We know that for some people reversals are very successful, others may have problems following the reconnection of their bowel and the closure of their stoma, so we welcome letters and stories from readers about their experience.
Ed.

Dear Editor

When Tidings comes through my letter box I can't wait to read it and everything comes to a full stop while I do just that.

Although I have a colostomy I realise that I don't have the problems that some of your other readers have. I'm a bit new to the "game"- just three years.

This edition of Tidings was an enormous help to me. The first article that boosted my confidence was by Iris when she says, 'she is nervous travelling too far from the comfort zone.' Because of a bad happening after my operation that's me and to know that someone else feels the same gave me such a buzz.

My family try to persuade me to have big holidays: go abroad, do a cruise etc. etc. The article from Julie gave me peace of mind. I too don't need to be "out and about". I have my senior citizens meeting once a week, mothers union at church, a weekly lunch at the church hall, my trip to the library and my cross stitch.

Can't begin to tell you how these two articles have helped me and stopped me thinking that it's only me that doesn't want to "fly my kite".

Regards
Jean (aged 80)

Dear Editor

Many thanks for sending me the magazine on a regular basis. It is so interesting and informative. I have yet to take my courage in both hands and say 'Yes' to a colostomy. I keep wondering if I can just go on coping without one. Then I consider the quality of my life and emotional state when accidents happen, the constant pain and discomfort, which result in my being tired and irritable with everyone.

I am sixty-seven, have chronic IBS, diverticular disease (two recent acute bouts resulted in hospitalisation) and a damaged anal sphincter due to a rather large baby and mismanagement by the doctor who delivered him by forceps in 1964. Together all three conspire towards me having a colostomy.

Reading Peggy Farley's article in Issue 5 brought it all home to me when she wrote about her life before the operation and her need to know where all the loos were.

I have a good friend who has had a colostomy for some years and is a volunteer in my area. She has promised to 'hold my hand' every step of the way and I cannot tell you how much this means to me.

Yours sincerely,
E.P.

To the Editorial Team

I had a colostomy operation eighteen months ago. On some days I consider having to change the bags a complete nuisance and on others simply an extra chore, like cleaning your teeth!

Shortly a decision will have to be made as to whether I want a reversal. My surgeon is non-committal, saying that the decision is mine - it seems that the operation is a practical proposal.

I wondered whether the team could include some information about reversals in Tidings or could ask readers about the pros and cons of having this second operation.

Your help would be greatly appreciated.

Yours Faithfully
P. K.

Dear Editor

In October last year I was rushed to hospital desperately ill with peritonitis and was very shocked to find I needed a colostomy operation. My recovery was painfully slow, not helped by the fact that I was discharged from hospital with a raging infection, which I had to cope with on my own. The antibiotics and pain killers caused constant sickness which made eating and drinking difficult and my weight dropped by two stone.

I am now mostly very well, my weight has stabilised nicely and my only problem is an occasionally overactive stoma if I eat too many vegetables.

I have been told I am one of the lucky ones who can have a reversal operation and I was delighted by that. However, now

Dear Tidings

I would like to share with Tidings readers my experience as to how I found myself with a stoma which has turned my life totally upside down.

Please do not misunderstand me, many ostomy patients are so thankful that the stoma has saved their lives, and yes, indeed, such is my case. I would certainly not be alive today if this form of surgery had not been available to me, but let me explain my worries and problem.

I went into hospital approximately two years ago to have a gall bladder operation only to wake up in intensive care with the surgeon leaning over me to say that during the operation he had perforated my bowel. At this point I imagined that all had been done to repair the damage, but four bowel operations later I was in danger of losing my life.

To cut a long story short, five months later I got home from hospital, with a TPN machine as my main source of nutrition and then a light diet to follow - all this, plus a fistula in the middle of my tummy. For many weeks I had daily leakages, causing weakness, soreness, despair and anxiety - my life was certainly on hold for that time. BUT the light at the end of this daily and nightly trauma was the fact that within a certain number of months - ten in fact - the fistula was going to be reversed and all would be well with me both physically and mentally.

August 2006 came around and I went into hospital with great optimism, in fact looked forward to the event. Going into hospital again for a major operation was just not a worry for me. My life would go back to what it was like before the fateful operation in June the previous year. So I had no fears, if anything I was elated.

My elation was short lived. After an operation which lasted many hours I woke up to find the surgeon beside my bed telling me I had a colostomy - one which could not be reversed. Apparently during the operation they found that my bowel, both large and small, was in such poor condition that he had had no choice but to leave me with a stoma. This was the first time this excellent surgeon had operated on me. As a result of the four previous operations, I had been left with only 70 to 80 cms. of small intestine. Some of my large bowel also had to be removed; this colostomy was the only answer.

Suffice to say I took this unexpected colostomy very badly and, since then, I have been unable to come to terms with the stoma. It seems outside my mental control to take and accept it and to know it will be with me forever leaves me totally bereft. I have lost my confidence, I feel unclean, seem to have no control over any action the stoma decides to take. Even ten months down the line I feel my life is totally at the mercy of this 'thing'. I have been told by many that I should try to be more positive; this stoma saved my life. I hear all the arguments and KNOW my life has been saved by the wonderful work of my surgeon, but I cannot move away from the fact my whole world has turned upside down and the quality is such I see myself without motivation. I have lost almost two stone in weight, my diet is so limited and so bland. Should I try something new, I suffer for days afterwards with a gurgling bowel, wind and lots of diarrhoea, plus many "accidents" with my pouch being incapable of handling the volume.

So, I am writing to find out if other colostomates feel the same as I do. I may be alone with such selfish thoughts, I just don't know, but this I do know, my depression is getting deeper and it now seems that all the tablets in the world will not take away this nightmare. Am I being thoughtless and thankless to all the medical profession who have helped me in the past - possibly - then again they do not have to live with a stoma. Sometimes I think that perhaps in this particular field of medicine unless the experts experience life with a stoma they really have no idea the degree of inhibition it entails.

I would welcome any feed-back from the chronicle of my medical experiences, be it argumentative or otherwise. I just would like to think I am not alone with all these feelings, that someone, somewhere, understands what I am going through. Help is what I need more than condemnation.

Kindest regards
Evelyn

Editors Note.

Most colostomates will have their small bowel, which is normally between six and a half and seven metres long, still intact. Some of the problems Evelyn is experiencing will not be common to the majority of colostomates as they are likely to be due to the large amount of small bowel which has been removed.

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.



Fundraising...

Donations

A reader sent us a cheque for £645.51 and this letter:

On Saturday the 24th March I gave a talk on 'Silverdale in Old Photographs' in our village hall. This was a fundraising function with receipts split equally between yourselves and our local hospice. Your association was chosen in recognition of the help you have given to my wife who is a colostomate. Many thanks
R.I.

A colostomate donated the prize money he won in a bowls competition and sent us this letter:

Last year I had two operations for bowel cancer, the first to form my stoma in July and the second in November to remove my lower bowel, rectum and anus. My hobby/sport is Crown Green Bowling, and

although I had to miss last season, I've just started playing again. I did manage to enter a bowls competition, the day before my operation in November 2006 and was lucky enough to win the tournament plus a trophy and £20 prize money and hope this small donation helps your finances a little.

Yours sincerely
R.T.

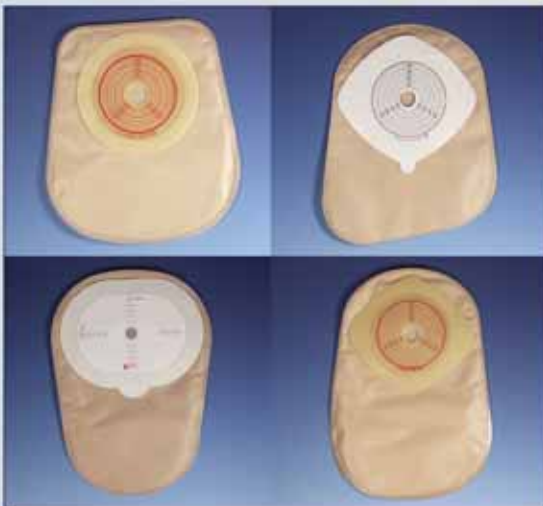
Legacies

Following our mini article about Legacies, in the Winter 2006 edition of Tidings, in March we were very pleased to receive a letter enclosing a cheque for £49100.50. This represented one third of the estate of one of our former members, Thomas Butler, who sadly died in June 2005. Although Mr Butler had not specifically left money to the association in his will, he had requested that his estate be shared between charities to be nominated at the

solicitor's discretion. The company decided to share the estate between the Cinnamon Trust, The Swindon Carers Centre and ourselves in recognition of the support that all three charities had provided for Mr Butler in his later life. This welcome "windfall" has meant that we have been able to start work on updating our literature much earlier than we had planned. We would like to thank Thring Townsend Solicitors in this respect. We do also, from time to time, receive letters in the office from funeral directors where people have requested that donations are made to ourselves rather than paying for flowers for a funeral. These injections of money, both big and small, really make a difference to the Colostomy Association and enable us to continue to provide advice and support to Colostomates countrywide.

Ray Goddard
Managing Trustee

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Name.....Mr/Mrs/Miss/Ms

Address

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Post code.....Tel.....

Stoma type: Colostomy [], Ileostomy [], Urostomy [] (please tick)

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

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

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

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

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

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

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

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

I want to become a '**Friend**':

- I enclose a cheque/postal order for £12.00 (made payable to Colostomy Association)
- I have completed the Standing order form on Page 46 (please complete the standing order form overleaf)
- Please tick here if gift aid applies to your donation (see overleaf for details)
- Please tick here if you require a receipt acknowledging your kind donation

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

Donations & Standing Order Authority



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

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

Title: _____ First Name: _____ Surname: _____

Address: _____

Postcode: _____

Tel: _____ Email: _____

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

To the Manager (Bank or Building Society) _____

Address: _____

Postcode: _____

Name(s) of Account Holder(s) _____

Account No: _____ Sort Code: _____

Please pay:

_____ NatWest Market Place Reading Branch

_____ 13 Market Place Reading RG1 2EP

Account Name: _____ Colostomy Association Ltd

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

The sum of: _____ £ _____

Amount in words: _____

Date of first payment: _____

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

Name: (IN CAPITALS) _____

Signature: _____ Date: _____

I 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).

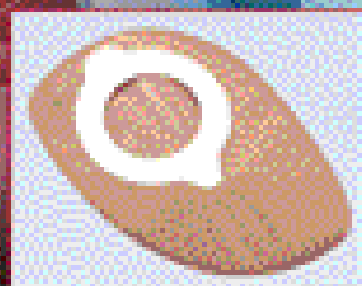
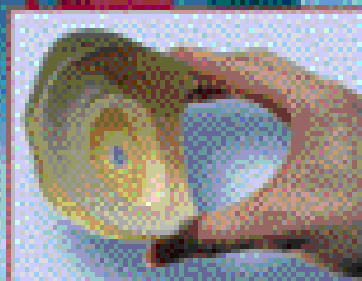
Signed: _____ Date: _____



Softima® Key Convex



Gently does it!



Softima® Key - The world's first truly guided two piece ostomy system is now available with convexity.

Convexity with comfort - Gentle, smooth and comfortable convex to fit closely for extra security with minimum pressure.

Secure and simple - The "key, guide and lock" system ensures precise, secure and easy connection every time.

B | BRAUN
SHARING EXPERTISE

B. Braun Medical Ltd - OPM Division - Thorncliffe Park - Sheffield - S35 2PW - Tel (0114) 225 9000 - Fax (0114) 225 9111 - www.bbraun.co.uk

For a free sample, simply fill in the form below and return using the FREEPOST address or freephone: 0800 163 007

Please send me a sample of:

Convex Flat

Closed

Stoma size _____ mm

Name: _____

Hospital Name: _____

Address: _____

Postcode: _____

Telephone: _____

Email: _____

B. Braun Medical Ltd - FREEPOST SF10771 - Sheffield - S35 2FZ

Open Days

The Colorectal Specialist Nurses at New Cross Hospital are holding an open day.

Date: Friday 17th August 2007.

Time: 10am -12noon & 1-3pm.

Venue: Jack Hayward Suite, Molineux Stadium, Wolverhampton.

Come along and meet stoma product manufacturers, delivery companies, local and national support groups and your specialist nurses.

For more information contact Catherine, Alison or Nicky 01902 694084

The North Glasgow Stoma Care Departments are arranging an open day.

Date: Friday 10th August 2007

Time: 11am – 2.30pm

Venue: Firhill Stadium (Partick Thistle Football Ground), 80 Firhill Road, Glasgow G20 7AL

The Stoma Care Nurses from all the hospitals in the Newcastle-Upon-Tyne area are holding their annual open day.

Date: 18th July 2007

Time: 10am until 3pm

Venue: Brancpeth Suite, St James Park Football Stadium, Newcastle-Upon-Tyne.

Support Group List Update...

We are updating our list of local support groups for 2007.

Please let us know the details of where and when your group meet and telephone contact numbers by contacting head office preferably by e-mail gill.herbert@colostomyassociation.org.uk

We will be publishing a complete list of local groups on our website.

Mr. Smith asks our readers...

Mr. Smith from Hull has written to ask if any of our readers have purchased a Braun Irrimatic electric irrigation pump and found that it's not for them. If so, would they be interested in selling it, in conjunction with a donation to Tidings? He has had one for about four years, finds it very useful and cannot consider life without it. However, as it is not available on prescription, to replace it would be expensive.

Mr. Smith can be contacted on 01482 641855



Tidings

Dedicated to Colostomates and their Carers

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

Tidings is your Magazine

If you have a story, poem, article, letter or any other item you would like to be included, please address them to the Editor and send them by email or post to the email or postal address given below and we will do our best to include them! We look forward to hearing from you!

Colostomy Association

15 Station Road

Reading RG1 1LG

Tel: 0118 939 1537

Freephone: 0800 328 4257

E-mail: cass@colostomyassociation.org.uk

For more information visit...

www.colostomyassociation.org.uk

Helpful Groups & Organisations

Other Ostomy Support Associations...

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

Support Organisations for medical conditions...

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

Alternatively write to:

RADAR

12 City Forum

250 City Road

London EC1V 8AF

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

Keys and Guides can also be purchased on line at: www.radar-shop.org.uk or by phone 020 7250 3222.