

Tidings

Dedicated to Colostomates and their Carers

DH Update...The future of stoma care could be seriously affected... Please read carefully...this will affect you!



Inside...

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Meet the Creator of the Colostomy Association.. and the Team

Dear nurse

Support groups

and much more...

Thank you for sending so many letters and e-mails to us about your concerns on the Department of Health (DH) consultation.

This consultation is based on the DH's desire to make changes into the arrangements for the provision of stoma appliances but to maintain (and where applicable) improve the quality of care to patients, whilst ensuring value for money for the NHS.

From your letters, you all share the same fear, that is, the future of stoma care could be seriously affected should the DH seek to make cost savings.

The 23rd January 2006 saw the deadline for submitting responses to the Department of Health. Our response represented over 17,000 people. Patient Power counts. Sadly, this is not everyone as there are over 60,000 colostomates in the UK, and overall there are about 120,000 people living with a stoma! Nevertheless, the DH received over 13,000 responses and 450 MP's sent letters voicing your concerns too.

In our response we explained the positive views and benefits of the current system and the potential effects if changes are not carefully thought through.

The Commercial Directorate have been very receptive and are keen to have discussions with Patient Associations. It is our aim to be part of the consultation process so that we can help to negotiate and bring about a successful plan which will be acceptable for everyone.

Please do not relax and be complacent, we need to maintain pressure on this situation. We therefore strongly recommend that you contact your MP and request them to support the following Parliamentary "Early Day Motions" 1281 and 1387 - there is no need to explain as your MP can look up and back these Motions.

**To view these motions please look on:
<http://edmi.parliament.uk/>**

In a nutshell, this is an important issue for all ostomates and future ostomates and the Colostomy Association will champion this cause!

A message from the Chairman of the Trustees...



One of the drawbacks of having bowel cancer or bowel disease and thereby becoming a Colostomate is that no-one likes to talk about bottoms or poo. We try and move on with our lives as if we didn't have this bit of plastic stuck to our bellies that sometimes has a mind of its own!

Many of us have known what its like to wake up, from major surgery, to face life with this new situation. It is not easy, it takes time and enormous courage. But you are not alone we are all here to be your companions and share the journey.

We need to be far more open in telling the world how great it is to be alive. We also need to be brave and not be complacent when it comes to our supplies, as these are now under scrutiny from the Government. We don't want changes that compromise our quality of life.

Fundraising

Now that we are self-funding charity, we need to get creative and think of ways to raise money that will enable us to continue to provide our services to old and new ostomates. Gill Herbert is now our fundraising Manager. We have all sorts of brilliant ideas to help raise awareness and money which can be seen on pages 3 and 4.

In my efforts to raise awareness, I have put myself down to give 10 talks on "Living with a Stoma" to local Womens Institute Meetings. So far, the WI have found these talks to be most illuminating and not at all embarrassing!

Colostomy Association Day

Our main aim is to celebrate our 1st Anniversary and call it Colostomy Association Day on 15th November 2006. In order to commemorate this day we would like all of you to think about having brunches, lunches, clotted cream teas, suppers, anything to advertise our 1st anniversary and also raise money.

On this day we will hold a raffle. One of the top prizes will be a week's stay in a luxury apartment (that sleeps up to seven people) overlooking the Helford River in Cornwall for the first week in June 2007. This is my personal contribution to the raffle and I can assure that all Ostomates needs will be suitably catered for! We plan to issue raffle tickets in a future issue of Tidings. Winning tickets will be drawn at the Head Office in Reading on Colostomy Association Day itself.

Happy 50th Anniversary

Wishing our "Sister" Patient Association, the ia (Ileostomy & Internal Pouch Support Group) a very happy Golden Anniversary with love from all of us.

Charter Roadshow

We are joining the Charter Roadshow where it will be starting off in Northern Ireland, moving South to the Republic of Ireland before coming over to the mainland UK. I will be joining the Charter Bus as it tours Southern Ireland, and hope to meet Friends (old and new) of the association along the way. See pages 10 & 11 for more details.

Love Sue

Have you become a friend yet?

The Colostomy Association is dedicated to everyone with a stoma, to make sure they do not feel isolated and receive help with the day to day practicalities. This service would not be possible without your donations and support.

We do not wish to charge a subscription, the original idea, as payments for a service are not eligible for gift aid. Instead we ask friends to make a donation each year for £12 or more, either by standing order, cheque or postal order. If you forgot to do this with Tidings 17, you will find a Donations and Standing Order form enclosed. If you become a friend of the Association you will automatically receive the quarterly edition of Tidings.

What is Gift Aid?

If you are a UK taxpayer and make a donation to charity, 28.2p extra can be claimed from the taxman, by the charity, for every £1 you donate. If, for example we receive donations totalling £10000 we will be able to claim, from the taxman, an extra £2820, this is a substantial amount of money. This is done at no cost or effort to you, all we need is your full name, address and postcode. So, please remember to include your details whenever you donate.

Fundraising the CA Way

When the BCA closed down at the end of December 2005 no money was transferred to the new Colostomy Association. Our bank balance was zero! Our only income so far has been from people becoming a Friend of the Association.

Donations are the first step to becoming self sufficient but, fundraising is paramount to the survival of the Colostomy Association. We receive over 500 calls per month, over 150 e-mails as well as many other forms of feedback. These people come to us for help and may not have anywhere else to turn if we are forced to close.

There are many ways in which you can help us, fundraising does not have to be major amounts, from £5 to £500...every penny counts.

We are currently putting a fundraising pack together, which includes an A to Z of ideas, sponsor forms, and general information on fundraising. As soon as we receive our Charity Registration Number this will be available.

Please contact us by e-mail cass@colostomyassociation.org.uk or by phone 0118 9391537 or write to 15 Station Road, Reading RG1 1LG, if you require a pack or any other information.

Colostomy Association Day

The 15th November will be our first anniversary and we are looking to hold a nationwide fundraising day, where individuals, groups, companies can get involved and organise something in their local area.

Ideas so far include:

- Big Breakfast
- Brunch
- Cheese and wine evening

Can you think of other ideas? Please let us know.

On this special day, we are also planning to hold a national raffle. There will be more information in the next issue of Tidings.

Involve your Support Group

'Bags of Support' in Frimley, Surrey raised £300 from raffles held throughout the year. This was gratefully received at this early stage and a wonderful example how money can be raised without too much effort.

You can help us to raise money by collecting the following...



Foreign currency



Printer cartridges



Mobile phones

We will be joining a recycling scheme soon. This requires little effort as a freepost envelopes will be sent to you directly, with money credited to our account. We will give more details on this in the next issue of Tidings.



Putting the FUN into fundraising...

A successful event does not necessarily have to raise huge amounts of money. All efforts are greatly appreciated. Fundraising can be hard work, but keep it simple, accept offers of help and above all ...enjoy yourself!

A vintage way of raising funds

Readers may have heard of John Fish from previous Tidings (issue 14). John is a seasoned fundraiser. John organised his 3rd Vintage show of classic cars, bikes and model steam engines. We recently received a fantastic cheque for £380, being the amount raised.



Loud Tie Week

Marcus Williamson from Marc's Garage Ltd raised a marvellous £185 during Beating Bowel Cancer's campaign "Loud Tie" week at work.



Parachute Jump

Jo Heathfield raised a super sum of £160 by bravely doing a sponsored Parachute Jump.



Reiki Sessions

Our lovely volunteer and Reiki master Joan West from Warwickshire, gave Reiki sessions and donated all the proceeds to us. We received a fab cheque for £150.

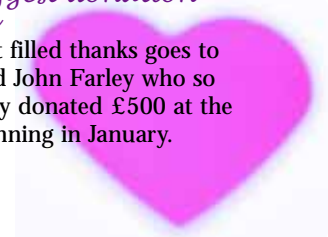


Don't send me flowers (or chocolates)!

During a recent spell in hospital Annette Scale cheekily asked her colleagues to make a donation to us instead of sending her chocolates and flowers! We would like to thank the Neath Port Talbot Youth Offending Team for their £50 cheque (we hope this proves that she did not eat her way through lots of choccies!)

Our biggest donation to date

Our heart filled thanks goes to Peggy and John Farley who so generously donated £500 at the very beginning in January.



The London Marathon...Bob & George want your Money!

Almost 40 years ago Bob Broadhead underwent extensive cancer surgery which left him with a permanent colostomy. Bob became a volunteer and an Area Organiser for BCA over 23 years ago and is still a volunteer for the Colostomy Association.

Now, on April 23, at the tender age of 70, Bob will be running in the London Marathon for the ninth time. "As you will have gathered, my cancer was caught in time," says Bob. He plans to raise money for the Colostomy Association.

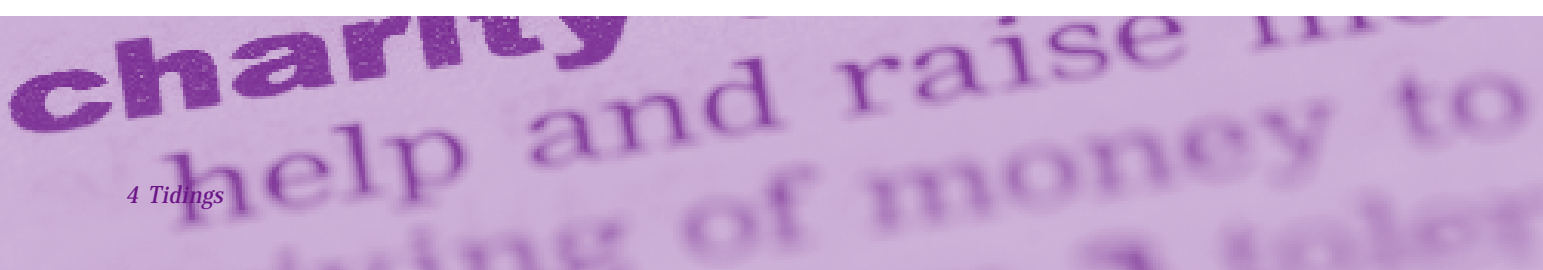


Marathon running seems to be a family thing, Bob's wife Jenny also runs marathons. Indeed, Bob is pictured here with his Great Nephew George who has been helping him to get into training.

"The golden rule is to set yourself a series of achievable targets. After your operation even your first visit to the local supermarket might seem daunting, but things will improve. You certainly don't need to run 26 miles to prove you can lead a full life."

Those wanting to sponsor Bob are welcome to send cheques (made payable to the Colostomy Association) to: Bob Broadhead, Colostomy Association, 15 Station Road, Reading RG1 1LG. If you are a taxpayer, please include your full name and address to enable us to claim Gift Aid on your behalf.

Wishing you good luck Bob from all your Friends at the CA



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POST



Reader to Reader...

Dear Readers...

I am 54 years old and I don't go anywhere because I am widowed and have other disabilities as well as a permanent Colostomy, it would be great to have a pen-pal to keep in touch with and I would love to go abroad this year but I haven't anyone to go with. I am a fun loving person (so people tell me!!!!) I just need a friend who can come out with me rather than having to be alone, all areas welcome to respond!..

From Mrs. M Fellows
Wigan, Lancs.

Dear Readers...

My two children were born with Hirschsprung's Disease and both had temporary colostomies, which weren't without problems. My daughter came first in 1975 when colostomy bags for babies didn't even exist, and my son arrived in 1980 by which time colostomy bags with teddy bears printed on were available.

We had genetic counselling before having our second child and it was thought it was unlikely to happen again as it was considered so rare, but it did happen

again so we had the same worries once more. My children were affected differently - one needed high fibre foods and the other needed low fibre foods. (A few years later when the treatment had finished I wrote a short story "When Lightning Strikes Twice" chronicling my experience of coping with two children with this condition.

I would be very interested to hear from any readers of your magazine who have been diagnosed with Hirschsprung's disease as to when and where they were diagnosed, what treatment they were given and how it has affected their lives since, did they have a family history of it? Have any of them gone on to have their own children and did any of their children inherit the disease? Have they had any other medical problems as a result of the Hirschsprung's disease, for example infertility? Both of my children (now adults of 25 and 30) are infertile and we are trying to find out if there is any connection between their infertility and Hirschsprung's Disease, or following surgery for Hirschsprung's Disease.

If there are any medical experts amongst you readers who may know answers to this particular question I would be pleased to hear from them.

I would like to hear from anyone who has had experience of Hirschsprung's Disease.

From Janet Tidswell
jantidswell@aol.com

If you would like to contact:

Mrs Fellows or Janet Tidswell, write, e-mail or phone us at Head office and we will pass on your details.

We look forward to bringing you this page again next issue, so please keep your letters/calls coming.

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15 Station Road
Reading RG1 1LG

Tel: 0118 939 1537

E-mail:
cass@colostomyassociation.org.uk

Web:
www.colostomyassociation.org.uk



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of the team
who will
take care of
your order.**

Meet Matt. Each day he receives hundreds of orders, but to him they're not just orders. This is your own personal request for your preferred make of stoma bag, cut to size and delivered to your home on time. He knows just how important it is. That's why each one is packed individually with care and attention, making sure that you receive your delivery without fail.

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Tom Robinson's Great Comeback Story...

Up until the age of 24, I was fit and healthy, leading a full and active life and had no reason to suspect that all this was about to change. I was diagnosed with Ulcerative Colitis in the spring of 2002 which came as an immense shock to me and had a huge impact on my life from both a personal and professional basis. I went from being an extremely active individual who regularly participated in football, golf, fishing, cricket and social activities, as well as being a full time firefighter to becoming an increasingly lethargic and worried person whose life was dictated by the geographical location of toilets! My condition was initially managed through a cocktail of various medications which helped to control the symptoms. Although I was aware that as a result of my diagnosis I would have good and bad times, I naively believed that if I kept taking the pills that this would be enough to keep the condition at bay. However, in the spring of 2003 I had a bad flare up which was not sufficiently managed by the medication and I was admitted to hospital onto a general medical ward for intravenous steroid therapy, which I hoped would remedy the problem quickly. I was given drip after drip for 10 days but the colitis did not settle at all, and I began to rapidly lose weight and feel more and more unwell. Whilst my family and my girlfriend Sallie, (who is now my wife) visited daily and kept my spirits high, I just couldn't help wondering when I would start to feel well again. I knew things were bad when my medical consultant introduced me to his surgical colleague! The date was Good Friday 2003, although I was told the bad

news that surgery was my only option and that it needed to be done sooner rather than later. I was told that it was necessary for me to have a total colectomy and stoma formation which didn't really make any sense to me at the time. Sallie, who also happens to be a nurse, explained what it all meant, along with several stoma care nurses.

Whilst I didn't like the sound of it at all I didn't really have many more appealing options and I was taken to have emergency surgery the following week.

The surgery went well and I recovered fairly quickly on a general surgical ward and was discharged home 10 days later feeling relieved to be home. However, after a couple of days I began to feel acutely unwell again and had severe abdominal pain. I was quickly reviewed and readmitted to hospital much to my dislike. I am told that during the course of the day I deteriorated rapidly and was admitted to intensive care. The following day I was under the knife again where it was identified that my small bowel had ruptured and I had peritonitis. During this 2nd operation the affected parts of my small bowel were removed and my stoma was refashioned. I was kept in intensive care for several days and was pumped full of morphine to keep me quiet!! As my condition improved I was transferred back to the ward to recover. Unfortunately due to my poor state of health my wound broke down and reopened leaving a gaping hole which had to be packed and dressed up to 3 times a day. I had by this stage lost over 3 stone in weight and

weighed only 8 stone 12lb. My stay in hospital on this occasion lasted 2 months and eventually I pleaded with Sallie to approach my consultant and ask if she could care for me full time at home. With her nursing background and her persuasive nature he thankfully agreed and I was brought home in a skeletal but very relieved state! My appetite improved at home as I was able to eat a more interesting selection of food than what was available on the hospital menu and I began to put on weight. After lots of TLC my wound eventually healed 10 months later!

My recovery was slow but sure and over the weeks and months I progressed. It was great to be back at home but I soon became frustrated with daytime TV and so focused on getting my fitness back and adjusting to life with a stoma. I started to go on regular walks and well as short bike rides and concentrated on eating a high calorie diet to help my weight gain. Six months after my second operation I was declared fit enough to return to work on light duties, mainly office work. Whilst this was a huge achievement it was not until a further five months later that I was declared fit to fight fires and recommence my normal working duties, which was such an amazing feeling.

Since regaining my fitness I ran the London Marathon in 2004 and raised over £1000 for the hospital wards where I was nursed during my illness. I have recently got confirmation that I have got a place to run for the *ia* in this years London Marathon too, and am currently training hard. I have also got back to playing golf and participating in competitions with my handicap of 5. I have also pursued my interests in travel and have been on holiday to America, where Sallie and I got married in June 2004. It was Sallie who entered me into the Convatec Great Comeback Awards where I was fortunate to be chosen as Great Comeback Awards Overall Winner 2004.

I, like other ostomates could not have got through all this alone. I have had tremendous support from my stoma nurses, my consultant and his experienced medical team and nursing staff and owe them my life. I have also received great support from the *ia*, the Colostomy Association, and Convatec. I also owe my deep gratitude to my parents, my wider family, my friends and work colleagues and in particular Sallie, my wife who has always given me tremendous love and support throughout. The final piece of the jigsaw has now been completed and Sallie and I are delighted to announce that we are expecting our first child in June. It just shows that there are no boundaries for people living life with a stoma and that people can live life to the full.

*Best wishes
Tom*

Sallie's Story

A Partner's Perspective

Three years into our relationship, Tom was diagnosed with ulcerative colitis. As a nurse by profession I was all too aware of the possible requirement for surgery, but like Tom I hoped that medication would be enough to manage his condition. Despite Tom's diagnosis, we remained a normal happy couple and I got used to the fact that when we were out together Tom would frequently disappear without warning. This would nearly always happen when we were out shopping and queuing to pay, but I soon realised that this behaviour was not as a result of a fear of paying but because of his necessity to find the nearest toilet!

I couldn't have been more shocked and distressed when after only Tom's second flare up, we were told that Tom's only option was emergency surgery. With very little time to adapt to this news my emotions ran high, and I was scared what the future held for Tom and for us both. In the little time available before the surgery I focused my energy on finding out as much information as possible to help Tom come to terms with what lay ahead. I felt so reassured when Tom asked me to be present when he spoke to the surgeon and the stoma care nurses before the operation. My involvement at this early stage allowed me to realise that Tom wanted and needed my support and it helped me to know that Tom took strength from knowing that I was willing to give him my continued love and support. The night before the operation we said an emotional goodbye, and whilst I didn't really want to leave him I was advised that he perhaps needed some time alone to adapt to the life changing surgery that lay ahead and to contemplate the future.

Tom thankfully recovered well from his operation, but the Tom I brought home from hospital was not the same person physically or psychologically and whilst I knew there would be a tough road ahead, I was quite unprepared for the next emotional rollercoaster. Tom's health began to deteriorate and he was readmitted to hospital where he became increasingly unwell. I am sure that day I became 'visitor from hell' in the eyes of the nursing and medical staff!! I felt completely out of control and helpless and just wanted someone to do something that would end this nightmare and make Tom better.

That night at 2am I received a phone call from the hospital informing me that Tom had been admitted to intensive care and advising that I should come to the hospital straight away. I will never forget the journey to hospital that night as I remember repeatedly putting on the car windscreen wipers to clear the 'rain' but when I did this the 'rain' did not clear.



It was not in fact raining at all! It was tears that were preventing clear vision from being achieved!

Despite my years of nursing experience, caring for critically ill and highly dependent patients I was not prepared for the sight I was about to see when I arrived at intensive care. After all it was the man I loved that lay in the bed surrounded by doctors, monitors, equipment and infusions. I felt so scared and frightened and helpless once more and found my nursing knowledge of what was going on to be a hindrance rather than a help at this time. Tom thankfully came through a second operation and after a few weeks recovery back on the ward, Tom convinced me it would be a good idea for me to approach his Consultant and beg him to let me take Tom home. As I bundled this 6ft 4inch bag of bones into the car I realised that the road to recovery and normality was about to begin!! At home I became Tom's full time carer, providing personal care as well as dressing Tom's surgical wound up to three times daily. Tom was at times a difficult patient, but I found this reassuring as I knew the old Tom was returning!! Whilst still bed bound Tom was applying for the following years London Marathon, so I knew I had my work cut out to get him well again!! The time we spent together during his recovery was very special and made us both realise that whilst it would take time for physical and psychological wounds to heal we wanted to work through these issues together and adapt accordingly.

Being in a secure and loving relationship helped us to have the confidence to face whatever came our way and I feel very fortunate that Tom involved me at every stage.

"I am so proud of the great comeback that he has made. He is now the happy, energetic and fun person I met 6 years ago and am so glad that Tom has embraced the support of family, friends and work colleagues. Supporting someone through stoma surgery is not easy. This challenge has been made easier for me by the support of others. The surgery has not only saved Tom's life it has given Tom and I the freedom to once again enjoy a happy and loving relationship".

Charter



Roadshow 2006

A unique event for people with a stoma



If you have a stoma, or a partner or relative with a stoma, then this is the event for you.

2006 marks the fourth anniversary of this unique event in Stoma Care. Over the past three years, thousands of ostomists have visited the Roadshow and have taken the opportunity to discuss products and services, and meet the national ostomy associations and nurse specialists.

This year we will be visiting a further 26 towns and cities in the UK and the Republic of Ireland, some for two days and others for one.

So if you have a stoma, do come along and share your questions or concerns in confidence. You will also have the opportunity to learn about the latest innovative ostomy products from Coloplast. Once again, there will be representatives from the Colostomy, the Ileostomy and the Urostomy Associations to offer information and support, together with Stoma Care Nurses, who will provide expert advice as required.

To check the most convenient location and opening times for you to visit the Roadshow, please see overleaf.

We look forward to
welcoming you aboard!



Charter Stoma Care is a complimentary journal for all ostomists! Each issue looks at lifestyle issues, medical insights, practical care and resources for ostomists. For your FREE copy, call 0800 783 1434 or register at

www.charter-healthcare.co.uk


The Ileostomy and Intestinal
Pouch Support Group

 Colostomy Association

 UROSTOMY
ASSOCIATION

 **Coloplast**

The Charter Stoma Care Roadshow will be located in the town or city centre where possible, in order to be accessible for all individuals, carers and relatives who wish to attend.

Here are the venues we will be visiting, with dates and times:

MARCH

Monday 27 March
Newry
Buttercrane Shopping Centre,
Buttercrane Quay
10am - 6pm

Tuesday 28 March
Belfast
Belfast City Hall,
Donegal Square
10am - 6pm

Wednesday 29 March
Ballymena
IMC Cinema Car Park,
Larne Road Link
9am - 4pm

Thursday 30 March
Omagh
Bus Station Car Park,
off Seelan Avenue
10am - 6pm

APRIL

Monday 3 April
Galway
Toft Park Car Park (next to the
Aquarium), Salthill
9am - 4pm

Tuesday 4 April
Limerick
O'Connell St, outside the
Penneys Shop & Pooches
Store 10am - 6pm

Thursday 6 and Friday 7 April
Dublin
Liffey Valley Shopping Centre
Fonthill Road, Clondalkin
10am - 6pm

Monday 24 April
Northampton
Abington St, Town Centre,
outside Primark
10am - 6pm

Tuesday 25 April
Bolton
Harpur Square
9am - 4pm

Wednesday 26 April
Colchester
Hollyday Inn, Eight Ash Green,
Abbotts Lane
10am - 6pm

Thursday 27 April
Basildon
Site by Wilkinsons, by St Martin's
Sq, behind M&S
10am - 6pm

MAY

Tuesday 2 May
Malden
Town Square, Barker Road,
(Near Lockmeadow Entertainment)
10am - 6pm

Wednesday 3 May
Canterbury
Rutherford Car Park, University
of Kent at Canterbury
9am - 4pm

Thursday 4 May
Greenwich
Charlton Athletic FC, The Valley,
Floyd Road, Charlton, London
10am - 6pm

Friday 5 May
South Kensington
Imperial College Car Park, by
Queen's Tower parking bays 151 -
159, Imperial College Rd, London
10am - 6pm

Monday 8 May
Ilford
Town Centre precinct between
Harrison Gibson & Argos on the
High Road 10am - 6pm

Tuesday 9 May
Leyton / Walthamstow
Score Centre 100 Oliver Road,
Leyton, London
10am - 6pm

Wednesday 10 May
Harrow
Zoom Centre,
Harrow View
10am - 6pm

Thursday 11 May
Uxbridge
Wyewale Garden Centre,
Piecl Heath Road, Hillingdon
10am - 6pm

Monday 15 May
Bellarm / Clapham Junction
Car Park in front of Sencall Court,
Winstanley Estate, (at rear
entrance of Clapham Junction
Station), Grant Rd,
10am - 6pm

Tuesday 16 & Wednesday 17 May
Epsom
Market Place,
High Street
10am - 6pm

Thursday 18 May
Basingstoke
Market Place, top of town
10am - 6pm

Monday 22 & Tuesday 23 May
Yeovil
Ivel Square The Queekam
Shopping Centre
10am - 6pm

Thursday 25 & Friday 26 May
Barnstaple
Library Square,
Gammon Walk
10am - 6pm

Tuesday 30 & Wednesday 31 May
Newport
John Frost Square off Kingsway
10am - 6pm (30th)
9am - 4pm (31st)

JUNE

Thursday 1 June
Llanelli
Festival Fields, Millennium Coastal
Path, Sandy Road
10am - 6pm

Friday 2 June
Cardigan
Quay Street Car Park, next to
Somerfield, Quay Street
10am - 6pm

Stop and read...this Important Notice...Now!

*Do YOU donate to BCA using
A STANDING ORDER?*

IF YES...

*Please IMMEDIATELY CANCEL
STANDING ORDERS to the BCA...
and contact your bank as money
donated to the BCA cannot be transferred
to the new Colostomy Association*

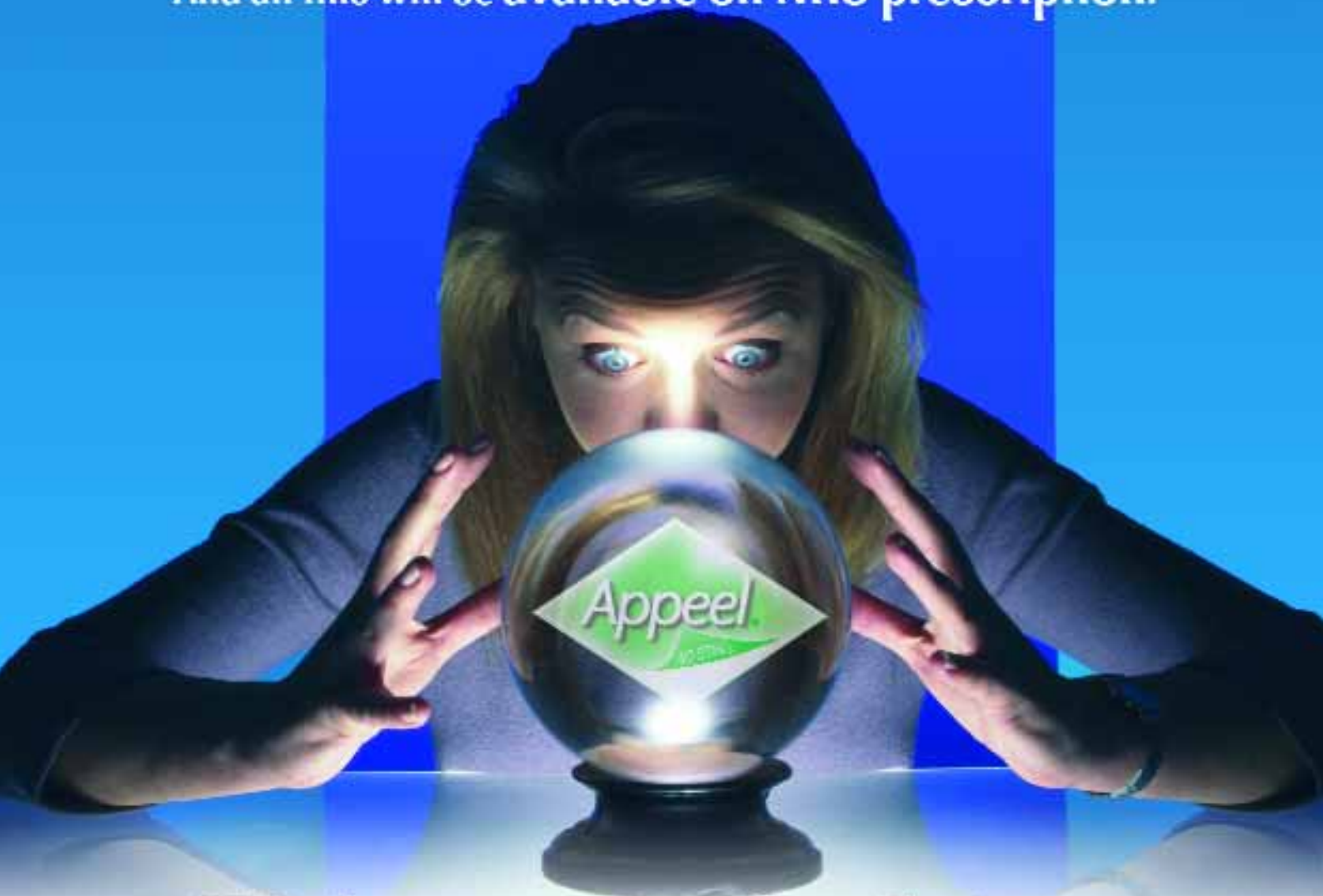
*Do YOU want to help support
the NEW CHARITY?*

colostomy  association

*All YOU need to do is complete
the form enclosed - thanks*

Stop and read...this Important Notice...Now!

I can see a bright future when you will be able to remove pouches and dressings without any pain, using a silicone based medical adhesive remover in a clever aerosol that will spray at any angle and moisturise your skin at the same time. You will also have moist wipes to easily remove the sticky residue that is usually difficult to get off. There will be no need to wash your skin because it will dry rapidly, leaving it clean and fresh, ready for a new pouch or dressing. And all this will be available on NHS prescription.



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A loved ones perspective...

A moving and loving tribute to my Mum...



“Mum loved receiving Tidings, and it gave her great comfort knowing people did care and understand and that she wasn't alone”

Dear Tidings...

It is with much sadness I write to tell you of the death of my mum, through bowel cancer she had a Colostomy 19 years ago, then had an Ileostomy after the cancer returned. My mum coped with great strength and dignity; she also had other medical problems such as asthma, gout and arthritis.

At 74 she decided to buy her council home and take on a mortgage, she always had an aim and a positive attitude.

At 88 after several falls mum fell and broke her hip, it was during her stay in hospital, she found the lack of attention and knowledge of her Ileostomy very upsetting. Mum went home walking with the aid of a frame.

Two or three months after she had a urology problem and had to be catheterised, she coped and never complained, a few months on she then had to have four skin cancer operations, one having to be a skin graft.

When she reached 90 years old, mum fell and broke the other hip. Whilst in hospital she had a gastric bleed, through an undetected duodenal ulcer. Doctors said she wouldn't

survive, but mum did, she stayed in two big hospitals, and still found it difficult to make staff understand her bowel function and stoma, sometimes experiencing her bag being allowed to be full so it burst, mum felt so embarrassed and degraded.

With lost dignity, she came out of hospital, walking with the aid of a frame but still taking care of her toilet functions.

After several infections one being MRSA and her second bout of double pneumonia and a great fight for life, she died at the age of 91.

Mum loved receiving Tidings, and it gave her great comfort knowing people did care and understand and that she wasn't alone.

So on behalf of my courageous mum...

*Thank you
Mr P. Holtham*

Diet...If you think that having a stoma may stop you from enjoying a variety of different foods - think again !

Having a stoma will require some changes to your diet, but proper nutritional management can reduce the common side effects such as dehydration, mineral loss, wind and odour without sacrificing enjoyment and diversity of food.

After Surgery

Bowel surgery that involves the removal of whole or part of the colon will affect the way food is processed, and how much water is absorbed, so initially your eating habits need to be adjusted until your body has adapted to these changes.

Immediately following stoma surgery, it may be wise to reduce your intake of foods which may cause blockage or irritation. These include high fibre foods such as whole grains, nuts and seeds, legumes, fruits and vegetables with non digestible peels, and stringy meats with lots of connective tissue.

Recovery

Excessive Wind, loose output and odour usually calms down as you recuperate. After a recovery period (4 to 8 weeks) gradually start to add new foods one at a time to see how they agree with your system. It is important to eat regular meals and maintain a diet high in protein to aid the healing process.

Dehydration & Mineral Loss

The colon's main role is to absorb water and minerals. Hence, after surgery your body will be prone to dehydration and also lose out on vital minerals such as sodium and potassium. To avoid dehydration drink plenty of water, and other fluids such as juices. Sport drinks can be used to replace valuable electrolytes or you can make your own. (mix 1/2 tsp salt, 1/2 tsp baking soda, 2 tbs sugar, 2 pints of water) Please note, if you have heart or kidney problems you should check with your doctor before increasing your fluid intake.

Gas and abdominal bloating

Wind can be embarrassing and inconvenient for anyone. Certain food and beverages can increase wind production, these include legumes,

(beans, peas etc.) brassica vegetables such as broccoli, cauliflower and cabbage, cucumbers, carbonated beverages and beer. Chewing gum and smoking can also be culprits too. Eating slowly, chewing thoroughly and also avoiding talking whilst eating all helps to combat wind problems.

If odour is a problem try covering the filter on the pouch (if one is fitted) with the little tabs provided in your box of supplies. You can control excess wind in the privacy of your bathroom by peeling back the filter cover and gently pressing the pouch. Please remember do not cover the filter when you go to bed, this may have disastrous results.

Foods that can increase odour production

If your ostomy pouch is not made with an odour barrier then you need to determine whether you are affected by any of the following: Fish, eggs, garlic, asparagus, spices, brussels sprouts and cauliflower.

Managing a watery output or diarrhoea

If your output is loose, try adding some soluble fibre (such as Fibo Gel) to your diet which helps to bulk and thicken the stool by absorbing water to form a gel in the bowel. This can be achieved by increasing your intake of foods such as stewed apple, apple sauce, banana, smooth peanut butter or rolled oats etc.

Social events need not be hindered by an ostomy. To reduce your effluent output for a night time outing, reduce your food and fibre intake as the day progresses. This will reduce the frequency of ostomy pouch changes at night.

While living with an ostomy can have its limitations, most people find that they are still able to enjoy a wide variety of foods that will be easily

digested. The following foods are generally well tolerated.

Breads and cereals such as rolled oats, tapioca or semolina, white smooth wholemeal bread, bagels, crackers, muffins, pancakes, rice and pasta. Milk and dairy products (unless lactose intolerant) such as yoghurt, crème fraiche, ice-cream, custard and a variety of different cheeses. Meat and meat alternatives such as beef, lamb, poultry and seafood, eggs, cheese and smooth peanut butter. Fruits and vegetables- stewed, tinned or fresh fruit with tough skins and seeds removed. For a treat try fruit sorbet. Well blended meat and vegetable soups, steamed, mashed or roasted vegetables are also well tolerated. All vegetables and fruit juices (an exception may be prune juice). If you are in a healthy weight range, enjoy some sweets such as marshmallows, meringue and jelly babies for an additional energy burst.

In short, having an ostomy does not preclude you from severing one of the great joys in life, Food! All that is required is an understanding of the condition, a preparedness to try different fare, a bit of imagination and of course a healthy appetite.

Note: Sickly feelings after major surgery are common and will pass with time.

This diet information is intended as a General Guide to help you through the Early days and weeks following surgery. Remember also we are individuals so what suits one person may not suit another.

For Help and Advice contact Your: Stoma Care nurse or Specialist nurse, GP, Dietician or Support Group.

Source of information: International Ostomy Association

Dear All

Last week I contacted you with a query regarding travel insurance and whilst cautioning me that it could be difficult to find cover, (my colostomy operation was less than 5 months ago), you very kindly sent me a list of insurers to try. For a two week holiday in the USA for myself and my wife I have been quoted a high of £1925 and a low of £523 and some refusals. I found another company on the net who you may consider adding to your list.

J.D (Consultants) of Farnborough, Kent (01689 856984) handled my enquiry differently from other companies in that they listened to my query, asked the standard questions but then instead of just giving a computer generated quote they gave me a code number and the telephone number of the medical underwriter at Fortis, a lady who questioned me on all aspects of my colostomy, its cause (rectal cancer), treatment I have received whether or not I was having any ongoing treatment or medication (no to both)etc. After answering all questions truthfully it was decided that I do not constitute a great risk and I was offered full cover at the normal rate (£53 each) with no extra premium, an offer that was sent to me in writing today.

The underwriter told me that all cases are dealt with on an individual basis and I hope this information can be helpful to other members.

Regards Alan B

Insurance get covered...

Here is our list of insurers that we know will cover ostomates.

We strongly recommend that you contact at least four companies. If you know of other companies that have treated you well and cover your medical needs, please let us know by contacting us at Head Office, or by phone 0118 9391537, or by e-mail cass@colostomyassociation.org.uk.

Age Concern Insurance

Tel: 0845 601 2234
www.ace.org.uk/AgeConcern/

Bishopscourt Insurance

Tel: 0870 777 9339

Their AllClear Plus Policy, is especially for travellers with disabilities or pre-existing medical conditions.

Chartwell Insurance

Tel: 0800 6524652*

We offer worldwide travel policies tailored for disabled or older people without fuss.
<http://www.chartwellinsurance.co.uk>

Churchill Insurance

Tel: 0800 085 2436*
<http://uk.churchill.com>

Co-op (new to the list)

Tel: 0870 5143301
www.cooptravelshop.co.uk
Offers cover for up to age 79 for a single trip

Direct Travel Insurance

Tel: 01903 812345
www.direct-travel.co.uk

FlexiCover Direct

Tel: 0870 990 9292*
www.flexicover.com

Free Spirit Pulse

Tel: 0845 230 5000

Insurance for travellers with pre existing medical conditions. (can't do annual worldwide - only single trips for cancer conditions)
www.pulse-insurance.co.uk

J.D.(Consultants) (new to the list)

Tel: 01689 856984*
Tel: 01689 851145
Tel: 01689 859102

MediCover Travel Insurance

Tel: 0870 735 3600

"Travel Insurance for those who have suffered from illness or have had an accident".
www.medi-cover.co.uk

*Coming soon...Exclusively for
our Colostomy Association
Friends!*

*When going overseas YOU have got to
have the Bigger & the Better!*

*We have noticed that our Readers love
to 'get around'! And you are getting more
and more adventurous. Therefore in order
to meet your needs we have developed
the new and must have 'Colostomy
Association Travel Certificate'!*

A New Travel Certificate

Our new travel certificate helps to give you the confidence to travel anywhere in the world and cope with the possibility of being asked questions at security check points. It is a handy wallet sized booklet which explains that the holder of the booklets has a stoma and the reason why the holder carries various medical supplies in the following of different languages:

- Arabic
- Croation
- French
- German
- Greek
- Hindi
- Italian
- Mandarin
- Polish
- Russian
- Spanish
- Thai
- Turkish
- Vietnamese

How do you obtain one? If you are already a 'Friend' of the Colostomy Association and given £12 or more, then just write, call or e-mail us and one will come to you in the post. Not a 'Friend' yet? All you need to do is complete the 'Become a friend' form and send it to the Head Office address. If you have lost your form just let us know and we can send a new one in the post.

Going on Holiday? Get covered!

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

Post Office

Tel: 0870 443 9721
Up to age 75

RAC Insurance

Tel: 0800 55 00 55
www.rac.co.uk/insurance/

Sainsburys Travel Insurance

Tel: 0845 300 3190
<http://Sainsburysbank.co.uk> (if not
related to cancer conditions)

VentureSure Travel Insurance

Tel: 0800 181532
(formerly known as TravelCare
recommended by *ia*
www.venturesure.com

* denotes good competitive rates
at the moment
Updated March 2006

Glyn Davies...National Assembly for Wales 7th February 06 Liberal Democrat Minority Debate - Access to New Drugs



Today's National Assembly debate concerns access to new drugs by people suffering from serious illness. I have some personal knowledge of this matter

Members who served during the First Assembly may remember that in 2002 I was diagnosed with colorectal cancer and underwent major surgery (an Abdomino Perineal Excision of the rectum) which saved my life. As an aside I should add that a few days ago I received the all clear following my 3-years-on colonoscopy and can now reasonably claim to be fully recovered.

Today is the first occasion I have referred to my personal experience in the National Assembly because I find talking about it difficult and do not want to be categorised as 'a cancer sufferer' by my political colleagues. However, I cannot allow this debate to pass without making a contribution about three important matters relating to how we deal with colorectal cancer, including the sensitive issue of access to new drugs.

Firstly, I want to make reference to the importance of screening for bowel

cancer. The reason that this matter is so important is that early diagnosis delivers such a very good chance of a full recovery. Every year over 30,000 people in the UK are diagnosed with colon cancer. Every year over 16,000 people die of the disease. It is the second most common cause of death from cancer after lung cancer.

Many of these people would not die if there was an effective screening programme. It seems incredible to me that there isn't more urgency in the drive for more effective screening. I had hoped that real progress was being made last year when a home test kit programme was announced for England, which it was reasonable to anticipate would eventually be extended to Wales. But even this limited programme is not progressing as we had hoped. I ask the Health Minister in our new Senedd today, to take screening for bowel cancer much more seriously. Action on this issue would save thousands of lives every year.

Secondly, I want to make a brief reference to the 'Review of Arrangements for the Provision of Stoma Appliances' that is currently underway as part of a wider review.

For those of us who have had a lower bowel re-section and for many others who have undergone gut operations a colostomy is permanent. This in itself can be a traumatic experience. It has been a blessing to me, as it has been for every other ostomate that the supply of stoma appliances is currently being handled with a wonderful efficiency. Now the system may be completely changed. There is a great deal of concern amongst ostomates and those who care for them.

I ask the Minister to be careful about this change. There is a real danger that the wonderful system now in place, widely trusted and applauded, is threatened by the Government's obsession with change.

The third point I want to make is about access to new drugs. For many years there has been a standard drug (5FU) used in the treatment of colon cancer. Now suddenly there are, in

existence, several new drugs of huge promise. These drugs have the capacity to save lives.

Last summer I was involved in huge publicity about a new drug named 'Zeloda'. This drug had been approved for use in Scotland but not in England and Wales.

Today we have a similar position with other drugs for other diseases such as 'Herceptin' which has been referred to so often in this debate. Another example of this sort of unfairness is the situation that exists for a friend of mine who suffers from Multiple Sclerosis. She has been advised, by her consultant, that Beta Interferon is the best treatment, but because she lives in Powys she cannot have it.

My message today to the Minister - is simple and clear. Give real priority to completing the testing and approval of these new drugs. I fully accept that this is a difficult and sensitive issue. I fully accept that the Minister can often be in a no win position. And I fully accept realise that the Minister cannot say 'Yes' to everything.

I close by making my final point. It is painful to watch someone you love, or someone you know well dying as the result of disease. But it is much, much worse when you know that there are drugs available that could help them to recover.



Our favourite Minister Glyn Davies tells us all about his latest battle...

Another political battle - Welsh Assembly v. House of Lords & Commons Rugby Match

I am slowly recovering from damage inflicted on my body following active service on behalf of the National Assembly. One Saturday morning, I led out a team representing the National Assembly for Wales to do battle with a Lords and Commons RFC XV. It was clear from the moment I arrived at the clubhouse that this 'friendly' was not what was written on the tin. The first supposed 'Parliamentarian' that I met, searching for the 'home' clubhouse, was a 22 year old gorilla of a man on the cusp of turning professional.



And then my team turned up - around 20 supposed 'veterans' from the London Welsh Rugby Football Club. Apart from the 63 year old leader of a male voice choir up in London to sing at a Grand Slam Dinner the night before, the entire team were lean and athletic, aged around 35, up for full on battle. Thank heavens that Brynle had pulled out. There was real danger that Labour would get their majority in the Assembly back.

I'd been out for supper the night before with 2 genial Lords, the Lib Dem Lord Dominic Addington and

the Lord Duncan of Faulkall, both huge wide men who I thought looked a touch slow - but when they started warming up they looked like 2 deranged bull elephants in the mating season. If the red benches ever break down into a fist fight, my money is on the Lib Dems. The Merthyr bruiser, Dai Havard, unshaven in skullcap was one of the prettiest boys in their side. I decided to slot in as blindside flanker with the rather negative ambition of defending the short side against a back row of obvious 'ringers'.

It was clear to me we were up against it but at half time we were only 10 points down and still in it. I was pleased that I had successfully tied up the blindside and had on one occasion got across to pull down the Rhondda flyer at outside centre, Chris Bryant, as he was heading for the line. At half time the singer from Merthyr opened a bottle of port and said that in his experience this would fortify us for what day ahead. Two of our team had already gone to hospital and I'd been knocked cold once and had a split lip and enough scratch marks on my back to keep a team of divorce lawyers going for a month - but the honour of Wales was at stake.

Five minutes to go and we were losing by 20 points. The Rhondda Flyer had scored a nice try while the Merthyr Bruiser had been replaced by yet another so-called 'parliamentarian' twice the size and ten times as ugly. For the tenth time I blocked the No 8 who off-loaded to the scrum half who

then chipped down the blindside. I was too knackered to chase back and just couldn't resist it. I flattened him with a body check, reasonably disguised as accidental. He took a few seconds to recover, hauled himself to his feet and launched a Mike Tyson like assault. Both teams waded in for a massive brawl which scattered all the wives, lovers, partners etc etc who were standing on the touchline. Then the final whistle went and we all went off for a drink. We're all dead keen for a rematch 'friendly' before the England-Wales game next year in Cardiff. Let me know if you fancy playing.

ED: We asked Glyn for the intimate details on how you play physical sport when you have a stoma. Glyn wore a stoma guard and wrapped a bandage around himself. If anyone is interested in contact or physical sports, we do have an number of volunteers who are only too happy to advise.



Meet the creator of the Colostomy Association...

Celia Waters *General Manager*

Celia started working for the BCA two years ago and became in charge of the overall running of the association as well as Chief Editor of Tidings. Thanks to Celia, Tidings has almost doubled in size and improved in content (and yet made considerable cost savings), the number of volunteers has increased as a result, the emergency help line has also become 24/7, every day of the year.

Celia does not have a stoma but her caring nature and professional knowledge has helped to enhance and improve the services of the Association. When it was discovered that the BCA was to close so suddenly, it was down to her commitment and determination that ultimately led to the creation of the new charity.



And the Team...



Jo McKenzie
Administrator

Jo is just a girl who can't say no! From starting as a 'Data Entry' volunteer over two years ago, Jo works full time and manages all aspects of our administration and is able to turn her hand to anything. She is part of the Tidings editorial team, Celia's right hand girl, your main point of contact on the Helpline, you can find her at some Open day events and she also represents the Association at medical professional exhibitions. Nothing is too much trouble for her, she is always willing to go that extra mile.



Gill Herbert
Fundraising Manager

Last July we were fortunate to have a new addition to the office, namely Gill Herbert. Initially Gill (took over from the lovely Val Richards who had retired) was responsible for all our literature packs. It was Gill's task to make sure these were stuffed full of helpful and interesting information and posted as quickly as possible. But Gill wasn't just a pretty face - she had lots skills to offer and now has recently become our Fundraising Manager.



Beryl Goddard
Support Group
Co-ordinator

Beryl is our newest member to the office team. She has just started and her first mission is Support Groups, please go to pages 34 and 35. Beryl is also a volunteer in the Frimley area and we will feature her full story in the June Issue of Tidings.



Have you ever wondered why some things happen in your life? Do you ask 'is there a purpose to this?'. Then sometime later... (maybe even years later) it seems to make sense.

Where does my story start? Ah yes, the power suits of the 80s, I not only remember these but I also wore them!

After my degree in Accounting Studies I started work as an auditor, whilst studying to get the professional qualifications. During this time I witnessed the birth and all too often the demise of organisations. It was always very frustrating witnessing a soletrader, partner, director or a board of Trustees ignore professional advice and make mistakes which would result in the end of the organisation. On the other hand, it was also very rewarding helping organisations form and grow.

So, into the 90's, I was happy with my career and after studying hard, passed my exams. Life was just dandy. But, out of the blue, my husband Colin announced that he was needed to work on a project in Thailand. Wow! A career break for one year!

The year's break became nine years. Apart from meeting lovely people such as Gill, and lunching like no other lady has lunched before, I also got involved in a number of charitable organisations. This included fundraising events and even regular newsletters.

Since 1993, I have had 14 different addresses and have lived in Thailand, Japan, Scotland, and Wales before returning to roost in Reading. My Son, Cemlyn (Colin and I are both from Welsh stock) was born in

Thailand and Carys, my daughter was born a Scot! Obviously we have had many next door neighbours, but our last neighbours in Thailand were particularly memorable.

Their names were Maureen and Dave, they came from Sunderland and Dave was also working for the same company as Colin. It was a first for Maureen - being an Expat that is and she felt like she was a fish out of water. Dave on the other hand was a laid back sort of person, he loved sailing, diving, and doing his engineering job. However, one day, we had a parcel delivered from the UK, which was meant for Dave. So being neighbourly I popped over to their place and knocked on the door.

Maureen and Dave were thrilled to see the parcel and thanked me for dropping it in. Then their story was revealed to me. A couple of years earlier Dave had bowel cancer and as a result he had a colostomy. The parcel in question contained Dave's supplies. Dave had tried the Thai supplies but the adhesive was too different in comparison to his faithful UK ones! This revelation about my neighbour's lifestyle had no effect on me, I appreciated their openness and thought no more about the lifestyle of a colostomate, it certainly did not stop Dave living his life how he wanted to.

All this was to change in 2004. I was sitting on the sofa at home in Reading looking forward to 'a bit of

me time'. Suddenly, the phone interrupted my thoughts. It was the temping agency that I had recently joined. It was Vicki "Celia, could you help out a charity, it will only be for three weeks?" The very next day I was working at 15 Station Road for the BCA and that was when I realised that living with a stoma can have it's difficulties - the day to day problems such as leaking and sore skin, the feeling of isolation, self-confidence and appearance issues to name but a few; I knew I wanted to help and make a difference and since that day I have not looked back.

Although creating the new Colostomy Association has been hard work at times - its all proof why things happen in our lives and it's usually all for a reason..

Celia Waters

Profile: Jo McKenzie

After being an at home mother of two fabulous children; (Now both aged 16 & 12) oh and lets not forget the cat, I had always planned to return to work at some point.

I wanted an office based job, so I decided that I needed to update my knowledge of computers. Yet this in itself was a very large step as at that stage of my life my confidence had hit an all time low, simply by spending a lot of time alone at home. Despite this fact, in 2002, off I went along to the local college and enlisted myself on an access course which included I.T (Computing) and Psychology. I found the whole experience great fun and rewarding but hard work. On completion of the course I still felt quite nervous in regard to returning to work (those naughty gremlins again!). Instead, I decided to consider offering my services as a volunteer (if and when needed). As if by fate whilst walking

by a Volunteer Recruitment Centre, one day in October 2003 I noticed an advert in the window for a data entry position within a charity organisation (British Colostomy Association). I went inside and had a brief chat, but I didn't fully understand what a colostomy was. So I went home and looked up the word 'Colostomy' in my dictionary. I then contacted the association and became their newest and youngest recruit to the team.

I found the work really very interesting, I enjoy helping others and can empathise with people who have been through an experience which is life changing. Back in November 2002 through the most unfortunate circumstances my father had to have an above the knee amputation and this experience has taught me a lot about having compassion for others. My Dad hated being in a wheelchair but he was determined to get back his life

and regain his independence and confidence and I am so very proud of all that he has achieved. The "if and when needed" basis became more and more frequent as my services were in hot demand! So, it was to my absolute delight in June 2005 that I was offered a full time position with BCA and I was so overjoyed to be part of such a great team. My happiness then turned to sadness when we were told of the BCA's closure. I was given the option to look elsewhere for a job but I was determined to see it through to the end. It was wonderful to be part of the creation of the new charity and to continue with all the great work that the Colostomy Association does.

Love Joanne

Profile: Gill Herbert

When Celia first asked me to 'write a brief history of myself', I was not impressed. How do you explain yourself and make it sound interesting to 17,000 people? Anyway, this is who I am and why I am here...

I was born and bred up north in Carlisle and until 1989 hadn't travelled further south than Pontins at Southport! I met my husband to be, Tim, in Carlisle, whilst he was working north of the border in Annan. We married a couple of years later and moved to Reading where Tim was then based. I had spent 14 years of my working life to that point with W H Smith as a trainer and as a deputy manager. I was lucky enough to be transferred to W H Smith in Reading so was able to continue working. However, within a couple of years Tim's work took us overseas to Germany, along with our one year old daughter Nicola. Germany was quickly followed by Thailand, where I travelled home in time for the arrival of Andrew a brother for Nicola. Within a few months we were on the move again, Singapore, then Indonesia then back to Singapore. It was on these travels that I met Celia.

On returning to the UK in 2003 I soon realised that I now had the time

to do something more useful than pack and unpack our lives between suitcases and continents. Nicola was thirteen and Andrew seven. And I realised my children were far more knowledgeable than I was on the computer, not acceptable! I signed up to do an ECDL through Reading Library and bring my computing skills into the twenty first century. Armed with my new found skills and a desire to do something that would make a difference I set about looking for a suitable local opportunity.

Over a glass on wine (or was it a bottle?) Celia persuaded me to come in to the office as a volunteer to help boost my confidence and practice my new computing skills. I found the work to be rewarding and interesting and was fortunate enough to be offered the opportunity to become an employee soon after. Up until that point my only experience of colostomy issues was through a relative. My management and organisational skills from working with W H Smith have been an asset.

My fundraising skills were as a result of a very close member of my family being diagnosed with breast cancer in 2003. I went to stay with her whilst she had chemotherapy. It was during this time that I realised the

importance of fund raising in order to support charities.

With a close friend, Kassi, we began our 'fundraising era'. Our first event was a family disco, in aid of Cancer Research; this raised over £2,000 and encouraged us to do more. Our latest event, in October 2005, was a black tie dinner which raised over £4,800 for the Royal Berkshire Hospital Chemotherapy Unit.

When the Colostomy Association was formed, I was fortunate to be offered continued employment. It is a cause I feel passionate about and look forward to working in the new team as Fundraising Manager. I promise to use all my skills, contacts, experience and enthusiasm to raise much needed funds which will hopefully make a difference to the information and advice available as well as to promote awareness in this area.

Love Gill

Top Tips from YOUR Trustees (or Mates)...



Tips from Sue...

Pancaking is a real problem for all colostomates, and although we hear of the term, we don't really understand what it is. This is my definition: When your poo, squeezes onto your body instead of going into your bag! One of the reason this happens is because there isn't enough air in the bag and so the poo doesn't take a downwards turn, it pushes sideways and comes out where you least want it! So! We need to lubricate our bags!



There are loads of products available from the various Supply companies and it is worth asking your Delivery Company to pop samples in with your supplies. So shove a bit of gel into your bag before you stick it on, give it a good rub and lets hope it stops that embarrassing, nasty, warm mess called pancaking!!



Tips from Adrian...

Irrigators Abroad - Do you find when you go to a hot country that your irrigation doesn't work as well as at home? If so, it could be because you are becoming dehydrated. By the time you feel thirsty, you are already partially dehydrated, so keep a water bottle with you and aim to drink the recommended two litres a day. If you don't, your colon will try to make up for the deficiency, in the same way that a camel economises on water. Remember, camels can't irrigate: don't be a camel!



Tips from Ernie...

It will soon be time for the forks, spades, and paint brushes and in my case the caravan to



emerge from winter hibernation.

When we see a little more of the sun our thoughts turn to those jobs in and around the house and we tend to go a "little mad", personally I Love it.

Almost ten years ago as a new forty something "bottom transplant" I gleaned information from every source available and at an open day I came across a stand and was interested to hear this person talking about hernias.

Thankfully not everyone with a pouch ends up with this problem but a great many people with stomas find that they develop a hernia in some cases for no apparent reason. After listening to and digesting this information I contacted my stoma care nurse for advice and soon had on order two forms of abdominal support.

One was a strong and sturdy support that would stand up to the rigors of continuous, heavy lifting and the other a light but firm support for the not so heavy jobs. By wearing these two forms of support at the appropriate times I have managed to stay clear of a hernia even though at times my poor old stoma along with my back has been abused.

For me personally I found that "Prevention was the better part of cure" But I have many friends with stoma's that have never worn a support garment who live life to the full without experiencing any adverse reactions or problems with a hernia. The choice is yours.

Tips from Beryl...

A prolapsed stoma must be supported through out the day with control pants to prevent the stoma coming out further. In extreme cases a belt with a stoma shield slightly padded in conjunction with control pants will ease the problem. The stoma will reduce when lying flat or with a cold compress. See you Stoma Care nurse as you may have problems with the appliance staying fixed.

Tips from Robin...

Drainable bags are more convenient when travelling, and essential if you might get struck down with "Pharaoh's revenge". The best tip I ever came across was to put some oil in a drainable appliance and work it round before fitting it, baby or olive oil, not 3 in 1. Please take care not get any oil on the sticky bits. If you have to change a bag on a train, wait till it stops!

Tips from Jackie...

When you get a bout of diarrhoea - take 3-4 (or more) jelly babies to be taken at least 30 minutes before each meal will help! If you cannot get jelly babies (or are a diabetic) make your own sugar free jelly and be sure to take some before you eat.

While we all use a peg to hold up our clothes while changing our pouches - ensuring they are free of our stoma area - try joining two pegs with a piece of cord, long enough to go around your neck area and hang down to peg on each side of your clothes. In this way you secure and support your clothing in a more balanced way.



Plants in Medicine -

Beetroot...

About beetroot...

Many readers will be aware of the effect that beetroot can have on the output of the stoma, everything turns red! But on the positive side this can be a useful method of gauging your bowel motion time.

Beetroot sales rocketed in 2005. This popular vegetable contains no fat, has very few calories and is high in fibre; it can be eaten cooked or raw (by grating it). The leafy green part of the beetroot is also of nutritional value and can be eaten boiled, steamed or fried. To maximise the goodness, when cooking, keep some of the stalk attached and be careful not to damage the skin, this will retain the colour and nutrients of the beetroot.

Beetroot, after the carrot, is one of the chief juices in the science of natural healing. The chlorine naturally present in beet juice acts to regulate digestion by controlling the peristalsis - (or natural rhythmical contractions of the gut) because of this, the digestion of food is much assisted. Eating beetroot is also a useful aid for constipation and piles.

Beetroot has for many years been used as a treatment for cancer in Europe. Specific anti-carcinogens are bound to the red coloring matter which supposedly helps fight against cancer and beetroot also increases the uptake of oxygen by as much as 400 percent.

On a lighter note, in mythology, Aphrodite is said to have eaten Beets to retain her beauty. Romantic readers will be interested to know that in folklore, if a woman and man eat from the same Beet, they will fall in love. Scientists are now investigating the aphrodisiac properties of this innocent looking vegetable as it is suggested that it can help to 'spice up your love life'.

Perhaps its worth a try?

Jo McKenzie

Beetroot and Cheese Toasties

Preparation Time 3-5 mins

Ingredients:

*2 slices of bread of your choice.
2/3 beetroot (thinly sliced)
Ground black pepper (sprinkle)
Cheese (of your Choice) grated or thinly sliced*

Method:

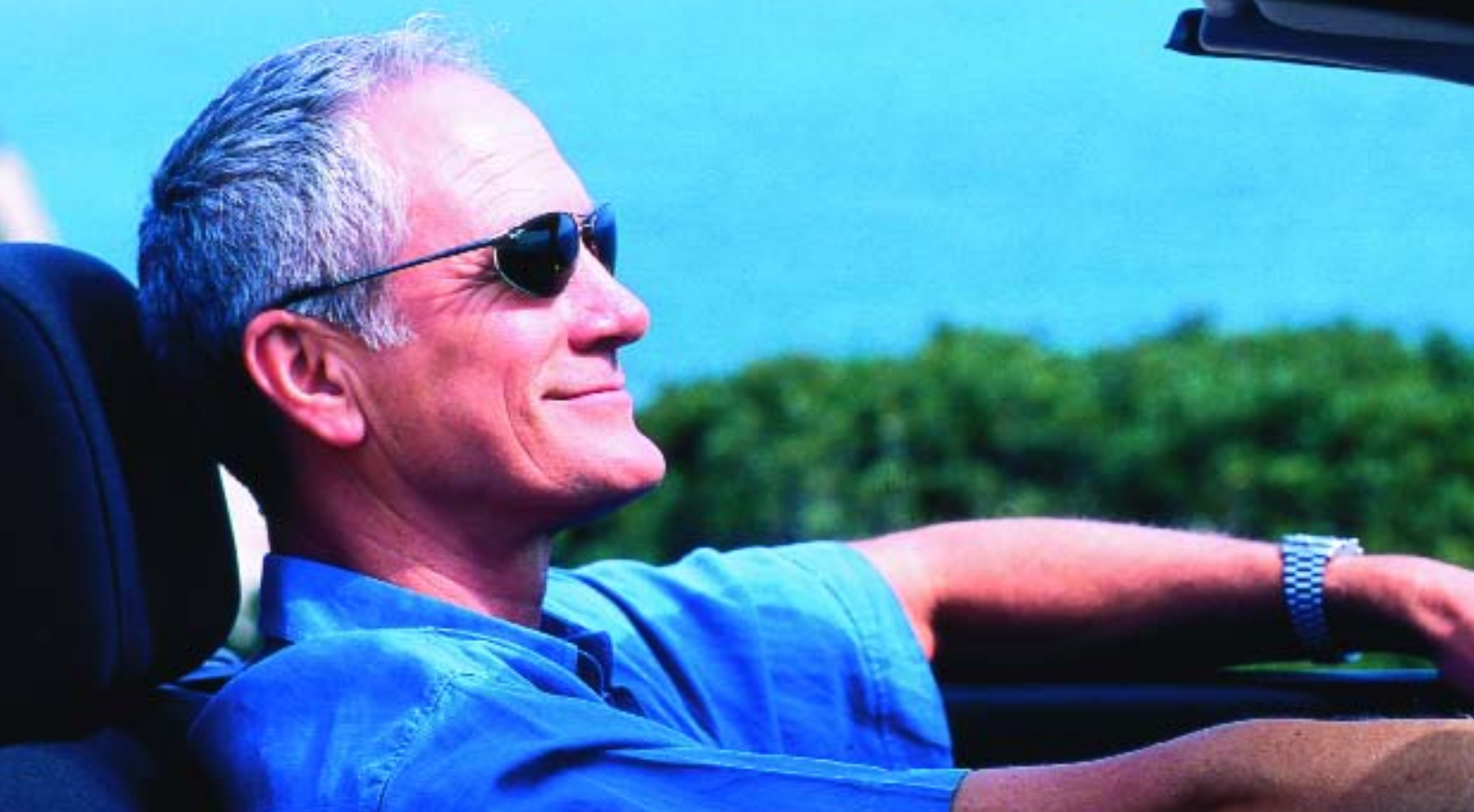
Lightly toast the bread on each side

Place beetroot slices on the toast

*Add Pepper & top with a generous helping of cheese
Place under the grill until golden brown*

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(FREESTYLE® USER)



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1. Pouch change & disposal study. C White PhD. Presented at WCET Conference, Brazil 2004.

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Address:

Postcode:

Tel. No:

I currently use:

My exact stoma size/type is:

mm

I prefer: Midi Maxi

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Dear Nurse...



Julie Rust, Clinical Nurse Specialist in Stoma Care at the University Hospital of North Staffordshire

Q: *I have only had my stoma for one month so therefore I know it will still be 'settling down' but I suffer from excessive 'wind' particularly in an evening and wonder if you have any suggestions to prevent this.*

A: Wind can be a major problem, especially in the early days after surgery. It should settle over time but certain changes in lifestyle can help. Firstly it may be due to the type of food you are eating. Certain foods can cause excessive wind, for example green vegetables and onions, although they may not affect everyone. Also talking whilst eating can cause extra wind, as can having fizzy drinks. Some people find changing the time of their

main meal of the day helps whilst others find they need to keep a food diary to find out which food affects them. If none of this helps it may be useful to try fennel (as a vegetable, as a tablet or mint or as a tea) or charcoal (as a tablet or biscuit available from herbalists).

Q: *Is it normal to feel pain around the site of a hernia? I have been experiencing pain and a bloated feeling for some time. What causes this?*

A: A parastomal hernia is caused by a weakness in the abdominal muscle allowing a loop of bowel to protrude through the defect. This can cause a swelling around the stoma which can lead to pain or a feeling of heaviness around the stoma itself. This often worsens as the day progresses. To alleviate this heavy feeling it is useful to wear supportive underwear or if this is not strong enough to see your Stoma Care Nurse to be fitted for an abdominal support. These supports are available on prescription from your GP but it is necessary to be measured for them first. This can either be done by your Stoma Nurse or she can refer you to a company or your own hospital for a fitting.

Occasionally a parastomal hernia can block causing a feeling of bloating or pain as the stool is unable to exit the stoma. This usually settles by itself, especially if you lie down which allows the trapped loop of bowel to settle back into the body. If you experience severe pain or the stoma stops

working completely and you feel sick or vomit, you must seek medical advice as soon as possible.

Q: *I am in a wheelchair because of spinal problems and have become faecally incontinent. My consultant says the only option is to have a colostomy. On the whole I am comfortable about this but I do have two questions. Will this mean my bottom (anus) be completely removed? Are there advantages/disadvantages that I need to consider?*

A: Having a stoma does not always involve having your bottom (anus) removed; this will depend on your surgeon and the operative procedure he/she is planning. If the anus is left in place you may find you get some mucous discharge on occasions or may even get a build up of mucous in the rectum. This build-up can lead to a feeling of needing to go to the toilet to empty the rectum and may even require an occasional suppository or small enema to clear the rectum of any mucus build-up. This can be done by a District Nurse in your own home if needed. It may be useful to speak to your Stoma Care Nurse regarding the specifics of your surgery. She may be able to arrange this either at home or in a clinic setting. This will allow you to get specific information relevant to your surgery and to ask any questions you may have. Your Stoma Nurse will have access to your medical notes and to your surgeon; therefore if there are any questions she is unable to answer



Dear Nurse...

she should be able to get specific information for you.

Q: *I have a parastomal hernia and am interested in doing some running or cycling soon – is this dangerous? Is weightlifting okay? What are the best forms of exercise so as not to aggravate the hernia?*

A: Having a small parastomal hernia is very common and should not restrict your lifestyle too much. However it may be worth seeing your Stoma Care Nurse for an assessment for an abdominal support, especially if you wish to take up more sport. Your Stoma Care Nurse can also refer you to see a physiotherapist who will be able to advise you on the correct sort of exercises to help to strengthen your abdominal muscles without aggravating your hernia.

Q: *I had my colostomy done two years ago. However, the last couple of months my bags have been leaking and my skin has become very itchy. What could have caused this? And are there any creams I can use?*

A: This may be due to an allergic reaction to either the pouch or to any supplementary equipment you are using, e.g. pastes, wipes. It could also be due to a change in the size or shape of your stoma which has caused the leak problem. This could then lead to sore skin from the effect of the stool on the skin. Before you try any creams, which can stop

the pouch sticking correctly, I would suggest you make an appointment to see your Stoma Care Nurse who can then assess your stoma, equipment and skin condition and advise on the correct treatment to solve the problems for you.

Q: *My husband has had his colostomy for sometime – that's not the problem – it's the odour in the bathroom after he has been. Unfortunately he doesn't seem to notice and I don't want to embarrass him by mentioning it. What can be done? Is it his diet?*

A: Excessive odour from a stoma can be caused by the food your husband is eating. Certain foods, such as spicy foods or onions can cause an odour and by changing the diet this can be resolved. You may find that by keeping a diary of what your husband eats and relating this to any odours you notice may help you to identify which foods cause the worst odour. Once you know this you can change his diet accordingly. You could also use a de-odourising air freshener in the toilet which may

help to neutralize the smell. You may also find that your husband is aware of the odour but is too embarrassed to mention it to you.

Q: *I have a lot of wind which I can control quite well with a drainable bag. My trouble is that it is quite smelly. Is there anything to help control the odour?*

A: Certain foods can cause more odours which can be quite embarrassing. If you are able to keep a diary of the foods you eat over a set period of time and try to link these foods to any particular days when the odour is worse. You should then be able to identify which foods give more odours and then alter your diet as necessary to improve the odours. Also charcoal tablets can alleviate the odour; these are available from many herbalists. Some companies also produce odour relieving drops which you can place inside your stoma pouch, speak to your Stoma Care Nurse for more information.



“Doctor, when can you put my Colostomy back?”



Dr. Chris Hall - Colorectal Surgeon at the University Hospital of North Staffordshire since 1995

Many patients are eternally grateful for their colostomy and consider it a blessing as it has either saved their life, or improved their quality of life as evidenced by many of the articles in magazines such as “Tidings”.

However, “When can I have my colostomy reversed?” is still one of the commonest questions that I am asked in outpatients, either during pre-operative discussions, when talking about making a colostomy, or post operatively, following surgery that has resulted in a colostomy. There are also patients who have had a colostomy that could potentially be reversed, but they are unaware of this fact, have never thought to ask the question, or have been afraid to ask.

This article is intended to give you a few hints as to why your surgeon gave you a colostomy in the first place, and how your surgeon decides if a colostomy is reversible, so that you can at least ask the question with more confidence and understanding.

Why have I got a Colostomy at all?

Talking generally, colostomies are made when it is considered unsafe, undesirable or technically impossible, to allow faeces to be expelled from the anus in the normal manner. If you do not know the specific reasons why you had your colostomy, you should ask your stoma nurse, your general practitioner, or your surgeon.

What type of Colostomy do I have?

Essentially, there are *only two types* of colostomy:- *an end colostomy, or a loop colostomy.* The features of each are summarised in the table below

End Colostomy	Features	Loop Colostomy
Usually on the left hand side of the abdomen	Site	Also usually on the left, but may be on the right, above the umbilicus.
One stoma on the abdominal wall. Occasionally, there may be a completely separate stoma in addition called a “mucous fistula.”	Appearance	One stoma on the abdominal wall, but with two holes, so it tends to be slightly bigger in overall diameter than an end stoma.
This one hole produces faeces into a stoma bag. If there is a second stoma present, (mucous fistula) it produces only mucus.	Stoma Function	One hole produces faeces, the other is basically redundant, but there may be overflow of faeces into this hole, and then down into the distal bowel and out through the anus.
The reversibility of an end colostomy often depends on where the other end of the bowel is!	Potential for Reversal	A loop colostomy is designed as a temporary solution in most cases, and most of these are technically reversible.
An end colostomy can only be reversed by finding the other end, and successfully joining them together. This may involve more complex surgery than that required to make the stoma initially.	Ease of Reversal	A loop colostomy can usually be reversed by just cutting round the stoma and stitching the two holes back together, without opening the abdomen, and is considered to be minor surgery.

I think I have a loop Colostomy...tell me more

This may also be known as a “diverting” or “de-functioning” stoma, because it is made to divert faeces away from “something” downstream. That “something” could be a blockage of some description. It might be a problem or disease that will improve if it is not in contact with faeces, or it might be a clever bit of surgical plumbing that your surgeon wishes to heal and mature before testing with the passage of faeces.

1. A “blockage”

The “blockage” may be a disease within the bowel wall, such as an inflammatory condition like diverticular disease, or a growth, such as bowel cancer. The blockage may also be caused by something squeezing the bowel wall shut, so that faeces cannot pass through, for example, the gynaecological condition, endometriosis.

It may not be possible to remove the cause of the blockage at initial surgery because the condition is not treatable at that time (eg a cancer that will be better removed after a course of radiotherapy to shrink it, or endometriosis which may be subdued by hormone tablets). It may be that your general health is too poor at the time of the surgery to remove the cause of the blockage. A loop colostomy may be formed above the problem in either circumstance. This is usually with the intention of improving the condition causing the blockage, so that it can be dealt with at later surgery, or improving your general health, so that you may withstand major surgery at a later date.

Some children are born with conditions that mean they cannot have their bowels open, such as Hirschprung's disease, meconium ileus in cystic fibrosis, or even an imperforate anus. It may be necessary to perform a colostomy within hours of birth under these

circumstances, and this is nearly always with the intention of reversing the situation at a later stage.

2. A problem or disease that will improve without being in contact with faeces

a) **Inflammation** in the distal bowel or rectum such as colitis may improve if the faecal stream is diverted whilst drugs are given to treat the disease. Once the disease is under control, then decisions can be made regarding further surgery which may include removing the affected bowel and restoring bowel continuity.

b) **Sepsis** or infection such as an abscess around the anal sphincter may be treated quicker, and heal better, if faeces are diverted away from the area whilst treatment is completed.

c) **Fistula formation** is where there is an abnormal connection between two organs which should not normally be connected, such as the bladder and the large bowel or the vagina and the large bowel. The cause of this type of problem is often difficult to treat whilst faeces are allowed to pass by that area, so a temporary diversion is employed, whilst the underlying problem is dealt with.

d) **Faecal incontinence**, where the cause is surgically correctable, such as childbirth injuries to the

anal sphincter, may be an indication for a temporary stoma whilst corrective surgery is carried out.

3. To protect surgical “plumbing”

Surgical anastomoses, where two pieces of bowel are joined together, may heal better if the new stitch or staple line does not have to cope with faeces going past it in the initial phase. Sometimes, such a join up may leak, and if there is not a loop stoma already in place, one may be formed at a second emergency operation so that less faeces leaks out through the defect at the anastomosis, into the abdomen. Healing may then occur, which allows the stoma to be closed, without further major surgery, at a later date.

Why might I have an End Colostomy?

It is a myth that end colostomies are performed because the underlying problem is more serious than in patients not having a stoma at all. End stomas are performed for three main reasons. Firstly, if it is essential that there is complete isolation of the faecal stream from a distal problem, secondly, if the disease causing the problem is removed, but it is unsafe to join up the ends of bowel at that time, and thirdly, if there is not enough bowel left at the end of the operation onto which the stoma can be connected.

1. Complete isolation of the faecal stream

This may be advisable if there is a fistula between the bowel and another organ (see “fistulas” above) which is likely to be a permanent state of affairs. This might be the case if the patient is so frail that major surgery to remove the cause can never be contemplated, or if radiotherapy given to cure another disease is the cause of the fistula.

2. Unsafe to join the bowel ends initially

Sometimes, the patient is fit enough to undergo removal of a disease at the first surgery, but the nature of that disease is unclear, and so the join up is delayed until there is histology and clarity. This can happen if there is a lump in the bowel and the surgeon cannot tell if it is cancer or inflammation such as diverticular disease. If it is cancer, there may be a need for radiotherapy or chemotherapy before the bowel can be rejoined. If it is an inflammation, the surgeon would want all the inflamed tissue and infection to settle before risking a join up. As a piece of bowel has been removed, the two ends are not close enough to bring them both out close together onto the abdominal wall. The patient will either have one end on the outside passing faeces into the bag, and the other secured on the inside waiting to be found

at a later date, or there will be an end stoma, and the other end will also be on the abdominal wall as a mucous fistula.

The underlying disease, your general health and the position of the other end of the bowel will all be taken into consideration before a decision to reverse the colostomy is made.

3. Not enough bowel left to perform a reversal

Sometimes, if the rectal end of the bowel is very short, the function of the bowel after a reversal may be so unpredictable that you would be advised to keep the stoma to maintain a good quality of life, even though technically a reversal is possible. Occasionally it is necessary to remove the anus itself because the disease process affects it directly. If you have no anus, you should consider the end stoma to be permanent. (There are some national and international centres that are working on artificial anal sphincters, or transposing leg muscles to act as a new anus, but these treatments are complex, largely experimental and most people are better served by accepting their stoma and enjoying life to the full *with* a bag rather than *in spite of* a bag!)

So, what do I need to know before I can ask that question?

1. *Why did I have a stoma?*
2. *What type of stoma do I have?*
3. *Has the problem that required a stoma in the first place been dealt with?*
4. *Am I fit enough for more surgery?*
5. *Do I want to go through with further surgery to get rid of the bag?*
6. *Do I have a reasonable idea what quality of life I can expect with the bowel back in continuity?*

Remember, whatever surgeons may tell you, they are simple plumbers, sorting out a bit of damaged pipework. If you can use the hints above to understand the plumbing, then you may already know for yourself whether or not a reversal is even possible, let alone desirable. Your stoma may well be for life, but it might only be for Christmas, after all!

*Dr. Chris Hall
Colorectal Surgeon*

*University Hospital
of North Staffordshire*

Life after a colostomy...

It appears to me that many people suddenly wake up after an emergency operation only to find they have a colostomy bag attached to them. I was one of those who, after collapsing in the doctor's surgery, came to my senses some 48 hours later after suffering perforated diverticulitis.

The reason I start with this fact is because I personally found the first operation relatively simple to deal with as opposed to the reversal! Of course the reason was that I knew nothing about the first one but plenty of time to worry about the second one.

I am often asked about my reversal but was rarely asked about the first one and the arrival of my 'bag'. Having said that I was told by the Ostomy Nurse that there are two types of ostomates; One who is very private and almost embarrassed to admit it and the second one she said was someone like YOU.

I was lucky, it could be reversed, I was eventually given a date, with three months to wait, but at least I could be prepared. I'm a Scout so being prepared was in my genes and I set about finding out as much as possible.

The one thing I recommend to anyone having an operation is to get fit, don't try and get fit, get fit. It appears to be the reason for the second op being better than the first, because, as I have already said, I knew nothing about the first one and was therefore not as fit as I could have been. Ironically, because of the removal of all the bad bits from my inside I was so much fitter anyway, with pure blood running through me and not poor knackered blood trying to fight off infection.

Now the bad part. I was ready for my reversal, fit as a fiddle, but mentally scared stiff. I'd never been in this situation before. I had never been 'prepped' for an op and certainly never been along a long cold corridor lying on my back watching the strip lights like a passing tube train. Then suddenly I awoke, still waiting for the knock out gas to be put over my face. I was back in the ward with my loving wife at my side. It was done, the bag had gone, I was back to normal again, but hang on, how on earth did they sew that amazing soft tissue together and stop it from leaking? What happens when I 'go' for the first time? What if?-Zonc, I slept for hours.

Now the really bad part. I've always loved the musical West Side Story. The famous song 'Maria' now began to haunt me but with the words changed to Diarrhoea, Diarrhoea, I've just met a man with Diarrhoea, and to cap it all I had traces of MRSA, and as a bonus the other, more deadly strain, which I cannot pronounce let alone spell. They had put me in quarantine, but to be honest a private ward was just what the doctor ordered. You can make a mess to your hearts content. In a way I was pleased to be on my own, I just wish I hadn't got a touch of MRSA.

Remember I said about getting fit, well it worked and as I had made a remarkable recovery I was sent home after about ten days. Well I thought that was the case, they had in fact sent me home because they didn't want me infecting the other customers! I have missed out the story about my first 'passing', but just to say I screamed for nothing, it was a dream, a wonderful release and nothing to worry about at all.

Then the fun started. Remember the time you broke your arm or leg and the muscles took forever to get strong again. Just think about your unused back passage muscle, yep, it was all weak and a bit saggy. I have now been without my bag for over a year and that muscle is still a bit weak. I still try and think of ways to exercise it!

I feel I was one of the lucky ones to have such a quick reversal, and I also know many people who want to keep their bag, they love it and have even given it a name. But for me, as a reborn 56 year old, I do not miss it for the world. OK, I have a little stinging leak every now and then, but only I know about it, and I'm alive. I'm very grateful for those clever surgeons who saved my life. Not too happy with the seamstress who sewed me back up, but hey, it's a talking point on holiday.

Good luck to all of you waiting for your reversal, just remember, get fit beforehand and make sure the nurses wash their hands!

Bob Chapman

Find out if you qualify for reduced water and sewage bill?

An enquiry received by the office recently concerned the charges made for supply of water and sewage. The enquirer's situation we believe is rather unusual in that water was supplied by one company and the sewage dealt with by another.

The person concerned was receiving a discounted rate for the water supply but not for the sewage. Letters to the companies and to the local MP apparently were not effective in getting the reduction for the sewage.

We have investigated the situation and passed on our findings, but it occurs to us that others may be interested in the general details concerning water supply and sewage charges.

Provision is made for reducing the charge for water and sewage for people with certain medical conditions. The Regulation is The Water Industry (Charges) (Vulnerable Groups) Regulations 1999 (Amended 2005). ISBN 0 11 085774 7 The full text of this Regulation can be seen on the internet at:
<http://www.opsi.gov.uk/si/si1999/19993441.htm>

Further Advice is available from

*OFWAT
 Office of Water Services
 Centre City Tower
 7 Hill Street
 Birmingham B5 4UA
 United Kingdom
 0121 625 1300/1373*

The Regulation applies to metered household customers who are protected from paying large water bills. The water bill will be 'capped' to the value of the average household water bill in the particular area. This means that it may vary slightly around the country.

The Regulation applies to households with three children under the age of 19 in full time education, or, includes someone with one of the following conditions:

- Desquamation, (flaky skin loss);
- Weeping skin disease, (eczema, psoriasis, varicose ulceration);
- Incontinence;
- Abdominal stoma;
- Crohns disease;
- Ulcerative colitis;
- Renal failure requiring dialysis at home (where there is no contribution by the local health authority for the cost of the water used.

To qualify under this regulation some one within the household must be in receipt of one of the following benefits:

- Council Tax benefit;
- Housing benefit;
- Income support;
- Income-based Job seeker's allowance;
- The New Working Tax Credit;
- The Child Tax Credit (Except families in receipt of the family element only)
- Pension Credit

It is also possible to qualify for a capped bill if a doctor certifies that there is a need for a significant amount of additional water because of any other medical condition.

We have been informed by OFWAT that the Regulation for Vulnerable Groups applies to both water supply and sewage.

Anyone who wishes to make a claim under this Regulation needs to contact their local water/sewage company.

Dear Colostomy Association...

I hope you can help!
I have a big problem with the cost of disposing of the amount of water I need to cope with my colostomy and mucous incontinence. I wondered if anybody else had contacted you about the same problem and if you know what I could do about it. After moving recently to a metered water supply, following the death of my husband, I am now faced with overall water costs possibly in the region of £500.00 per year instead of the £180.00 unmetered supply I had before. The Mid Kent Water, whom I buy my water from, have placed me on a medical tariff but Southern Water, who takes my sewage, refuses to do the same as I do not claim a means related benefit.

I really feel that somebody has to make a stand on this subject to help other people in the same position. I just do not understand why one company will allow me medical rate assistance and another will not. I have asked the Consumer Council for Water to ask the following questions to Southern Water:-

1) The criteria to be accepted on the assisted tariff from Southern Water states you must be suffering from a medical condition. Surely the fact that I am suffering two conditions on their accepted list would indicate my desperate need for assistance even though I do not claim a means tested benefit!

2) I was told when I considered moving to my present house that I WOULD qualify for the medical tariff by both Southern Water and Mid Kent Water. If I had thought I would not qualify it would have affected my decision to move to this location. I was advised by Southern Water that once Mid Kent accepted me with all the evidence I was asked to submit, Southern Water's acceptance would be routine and it would not be necessary to provide more medical proof of my conditions. This was obviously not TRUE and I feel I was badly misled.

3) Why are Southern Water charging me for removing all my sewerage when in fact a lot of my clinical waste (that would normally be disposed of by mains drainage) is taken away weekly by Maidstone Borough Council). They are charging me for a service they are not providing!

4) I would like to know now what the point is on me being on an assisted tariff with Mid Kent Water. The fact that Southern Water base their charges on the amount of water I am being supplied with by Mid Kent Water means that I will still be afraid to use the amount of water I actually need because of the cost Southern Water will charge me to dispose of it.

Please understand that I am not asking for cheap water. I am well prepared to pay both companies the normal amount for water and sewage disposal based on the normal usage of a single person living on their own - in spite of the fact that some of my sewage is disposed of by Maidstone Borough Council. This alone will more than double my previous bills as I did not pay for sewage disposal at my previous home but all I am asking for is it to be capped at that rate so I am not afraid to use more as and when my medical conditions dictate.

I am in receipt of benefit...Disability Living Allowance and Invalidity Benefit (apart from the incontinence and colostomy, I am also registered partially sighted and NO, I am not quite the wreck I sound) but these benefits are not earnings related so do not count. I live on my own so no other benefits are coming into my home.

I have provided hospital evidence of my problems and they have been accepted. It is just the pure fact that I am not claiming poverty from the state that Southern Water are basing their decision on....maybe I should sell up, squander any savings and live off the State!

Sheila Wicks

Support Groups....Why not get involved?



*Beryl Goddard
Support Group Co-ordinator*

Do you have visions of a dingy room, where a small group of people sit in a circle drinking lukewarm coffee and a horrendous leader whose ambition is to make you feel uncomfortable? Think again...

For those of you who have read my previous article (December 04) you will already be aware of the importance that I place on being in touch with other Ostomates and being able to share experiences, good and not so good.

I have been attending my local support group at Frimley Park Hospital for many years and have been a committee member for the last three years. We meet on the last Saturday of each month, in the very comfortable, and large, ante-natal department of the hospital. It is great for both socialising and for our guests. We organise a range of events over the year to cater for all tastes. Events already planned for the coming year include talks on the Transplant Games and Hearing Dogs, visits by a Consultant Urologist and a Ramblers Group, an Antiques Roadshow, a Suppliers day and finally a Christmas Party.

I feel very passionate about Support Groups. Some people will have a misconception of them i.e. a lot of sad people complaining to each other. In truth from my experience, they tend to be quite the opposite, people living their lives to the full, whether it be working full time, working part time and looking after the grandchildren, playing golf or singing in the local choir and, yes, having great holidays all over the world or just enjoying

retirement, but most of all people living their lives. Yes, we do talk about our stomas, it's great to be able to share a tip, or problem, or mishap with somebody who really knows exactly how you feel. It is hard to walk through that door the first few times, it's not easy living with a stoma either, but we do! Over the years I have met and have become friends with a wide range of people of all ages who have encouraged me as I have them.

I have, in the last week joined the team at the Colostomy Association and with your help will be adding to and updating our current list of Support Groups. This will enable us to direct callers to a group in their area.

If you are currently attending a group, or are aware of one in your area, please give me a ring, drop me a line or send an e-mail with details.

*Best wishes
Beryl*

Open Days

Venue: South Somerset Homes Conference Centre (on the outskirts of Yeovil), and there will be ample parking available.

Date: Saturday 6th May

Time: 10.00am-3.00pm

Venue: The Education Centre, Fieldhead Hospital (opp: Pinderfields Hospital, Wakefield)

Date: Tuesday 30th May

Time: 10am-4pm

Organised via the Stoma care nurses from the Pindafields Hospital

Venue: Guildhall, Market Square, Salisbury

Date: Wednesday 17th May

Time: 2pm-5pm

Open / Information Day

We hope you find this day useful and informative. It is aimed at all ostomists and their families. We hope the exhibition will keep you up to date with new appliances and accessories which can aid you and/or improve your quality of life. The aim of the speakers is to share stoma care knowledge. We hope you will be able to join us. Robert Azevedo-Gilbert (Chair)

Professor Christine Norton MA RGN DMS PhD

Nursing Consultant at St Marks Hospital

Gillian C Taylor RGN BN MSc Onc Cert

Macmillan Lecturer @ Kings College London

Sarah Varma RGN

Stoma Care Nurse St Marks Hospital

Saturday 3rd June 2006
10.30 am



Inside Out Stoma Support Group
St Mark's & Northwick Park Hospital Stoma Care Dept

OPEN/
INFORMATION
DAY

Incorporate with St Mark's Hospital
Foundation
Charity Registration 1088119



Support Groups

Trafford Bowel Support Group

Venue: Macmillan Centre, Trafford General Hospital, Moorside Road, Davyhulme, Trafford
Date: First Wednesday of the month
Time: 2pm-4pm

Totally informal but most helpful for ostomy patients wishing for support and everyday help and information.

Contact: Jackie Carey
Tel: 0161 748 9659

CUPID (Colostomy Urostomy Pouch Ileostomy of Dorset)

Pop-in sessions, 'an informal get-together for patients, partners and friends for support and information shared'

Pop-in sessions at Christchurch:

Venue: Howard Centre, Christchurch Hospital
Date: Tuesday 11 April, 13 June, 8 August, 10 October, 12 December
Time: 2pm-4pm

Pop-in sessions at Poole:

Venue: - Broadstone Methodist Church, David Jones Room, The Broadway, Broadstone
Date: Tuesday 9 May, 11 July, 12 September, 7 November
Time: 2.15pm-4pm
Contact: SCD 01202 704 813 or 01202 483 303
Beryl Andrews (co-ordinator)

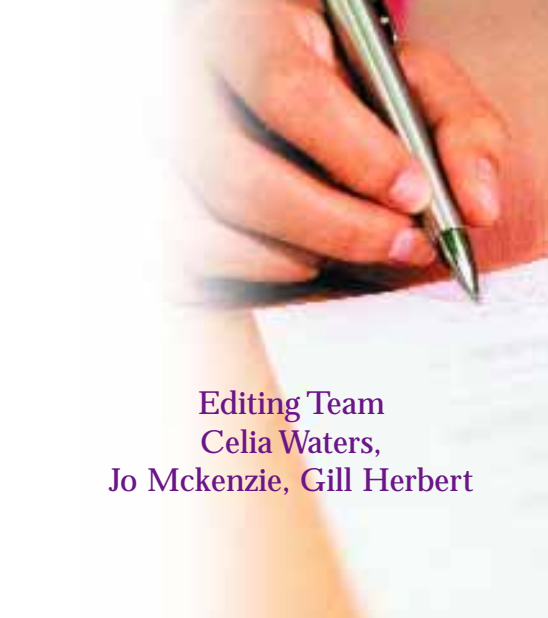
Countess of Chester Support Group

I am currently coordinating a new support group for members who live with a stoma having had their operation at the local Countess of Chester Hospital.

The idea came from our stoma nurse, but the group is intended to be run by the members themselves and I was volunteered as the coordinator. Our first formal meeting was Christmas 2005 and we have agreed to hold another meeting on 5th April 2006.

One of the areas which the group expressed an interest in was the issue of obtaining insurance cover both domestic and travel.

Contact: David Burgham
Tel: 01244 310461



Editing Team
Celia Waters,
Jo Mckenzie, Gill Herbert

Readers Writes

Dear Editor

Having had my Colostomy since Feb 2002 I rarely see a stoma nurse now and have little contact with other fellow ostomates. Therefore, like many readers, the magazine brings the feeling of comfort of not being alone, plus the uplifting news, helpful articles and tips.

N.B. to the question of holiday insurance abroad for the over 70's last year we found Age Concern helpful in this matter.

June Winters

Ed We have a list of ten insurance companies that have been found to be helpful to ostomates including Age Concern. We have printed this list on page 16. We are always on the look out for new companies, please contact us and let us know.

Dear Editor

Although, I know of no one in my area with whom I could meet to discuss the intimate problems of a Colostomate, so it is comforting to know that I can speak to the Association by telephone and seek their advice. My Colon cancer operation was five years ago, followed by another operation two years later and, though not a lover of my detachable bag, I can live with it and indeed bless it for granting me, at 85

years of age a pretty good life, and I hope with many more years to come. Good luck to your efforts

Roy Scott

Dear Editor

I laughed at your suggestion about a competition for 'who has done a bag change in the most prestigious place?' – what a great idea.

My best happened in October 2005 when I visited St Peter's Basilica in the Vatican and had to use the disabled loo there – it was heavenly!

Gillian Duncan

Dear Editor

It is one year since I have needed a colostomy. After major surgery at 85 its been a challenge to learn to cope with a new way of dealing with 'poo'!! I was encouraged with the way others coped, and led full lives. I started with having to change three times daily and my poor skin was raw. I dreaded having to remove bag. Then I discovered aloe vera wipes. Such bliss!! I gradually healed. Since then I've now found out about the bag with Velcro fastening and only change twice weekly. This enables me to go on coach holidays, and weekly social activities I can drive myself to. I've learned there's nothing that you can't manage to do when you are older. It just takes a bit longer!! Good luck in your new venture. It must give hope to so many.

Betty Rudling

Dear Editor

I received the last issue of British Colostomy Association, but which is now sadly no more. I am an OAP with a fixed income but am never the less anxious to support the new born Colostomy Association.

I have had a colostomy myself for 20 months, and realise that it is for the rest of my life for me! But with your magazine's quality of presentations, and the way other people write about their experiences with having to

accept a colostomy, it makes me feel (not so alone).

I wish our new organisation the best of luck and together we can all look forward to a confident future.

John Wheeler

Dear Editor

I was diagnosed with bowel cancer and subsequently had a colostomy in October 2004 after one weeks radiotherapy treatment. Due to complications I was in hospital for four and a half weeks. During this time I was having hallucinations due to morphine tablets and was surprised to be asked to visit the Mental Health Section, where I was interviewed by no less than three doctors (all in white coats)! I had visions of being whisked away as being mentally unstable but fortunately I passed the test and returned to the ward.

A holiday had been booked for April in Tenerife with the family and I therefore declined the offer of six months chemotherapy because of the possible side effects. I was able to enjoy a weeks relaxation in the sunshine, with no pouch problems. Since then my daughter and son-in-law have moved to Moscow, where he is employed by BP for two years. We decided to visit them last month for a couple of weeks and here again there were no problems, either on the flights or in their home. I must admit that on both occasions I was a little anxious as to how things would work out, but I need not have worried. At present I change only once a day, but judging by the letters in your magazine, two or three times seems to be the average frequency. Perhaps I am one of the lucky ones.

Whilst I was in Moscow I was able to resume my visits to the gym for a workout and back home I have resumed my weekly games of badminton. I celebrated my 80th birthday in September and one of my badminton colleagues is 83! So there's still life in the old dog.

May I say how much I appreciate reading 'Tidings' for the useful tips and interesting accounts of how other colostomates cope with their problems.

Geoff Lenthall

Readers Star Letter... "Have a laugh with Tony"

Dear Friends...

Thanks for Issue 17 of 'Tidings', as usual, a super read and so informative. Pat on the back for all of you - hope she's not too heavy!

So its goodbye BCA and hello CA, we all have to move with the times (prefer the Sun myself) and my sincere hope is that all the ex staff of BCA find employment to their liking very quickly. There is never a good time to be out of work.

Having lived with a colostomy for twelve and a half years, I blame it for my still being able, at 69, to enjoy a wonderful wife, two lovely daughters and twin grandsons. What a bonus eh!

Though I had exceptionally good attention by consultants and staff for two operations within 4 days at Doncaster Royal Infirmary, followed by a six week course of radiotherapy at Sheffield's Weston Park Hospital five months later (I had a thrombosis shortly after my cancer op). I tell everyone that I learnt more about my condition and future lifestyle from 'Tidings' than anywhere else.

The realisation that you are not the only one in the world with a stoma is a comfort in the early days for a start. Then, reading that someone else has the same 'problems' as yourself with things 'colostomate-ish' relieves worries no end. I thought that I was the only one who tripped off to the bathroom in the early hours to 'change', and remember the relief of reading that others did just the same. Have any of the appliance manufacturers come up with a set of

landing lights for base plates and flanges for when you are on holiday, and doing an involuntary night shift? The article 'Parastomal Hernias' in the last issue of Tidings was a case in point of a worry being explained to patients. I have a big one (naughty you if it flicked through your mind that I was boasting about another appendage) which I sometimes wonder about. Reading the article put things into perspective, knowledge being better than speculation, though I'm still contemplating some kind of light belt to ensure security. We do a bit of country rambling and I dread a pouch coming adrift or leaking in an inconvenient spot. I suppose the uncertainty is mainly in the mind, perhaps that's where I should stick my pouch..

In my short time as an ostomate, pouches have improved so much and we now have soft and pliable flanges for two piece sets which are truly comfortable. I reckon that we all owe a debt of gratitude to the manufacturers and their advisers. Technology is great, I just wish that I could catch up on the computer! Mine has a mind of its own, has 'off' days when it does 'nowt I tell it to do, and then decides that it won't talk to the printer. My eldest daughter, who lives at the other end of the country, calls her laptop 'That b..... thing' and I'm beginning to think that she may be right, or maybe it's me tapping the wrong tabs. If it is me, perhaps my daughter has inherited a family trait!

'A trip down memory lane' triggered a topic which is a favourite of mine.

We don't talk about our rear end problems openly. Many other Europeans do. All my relations and friends know of my stoma. My wife and I have found it the easiest way to explain and excuse that noises which we all know are uncontrollable. Why is it that you can be in a noisy environment, but should it go quiet suddenly, that's when your stoma decides to speak up for itself? Answers on a non-dirty postcard please to 'Tidings'.

My best wishes to CA. May it enjoy a long and fruitful life for all our, (and those who might follow us), sakes. As I said before, it has helped and informed me many times.

Everything good to all ostomates and those who care for, inform and put up with us, may you all continue to enjoy life to the full. Some of us are fortunate to have been allowed a second chance, spend the time well. Finally, to you ostomates, just think about we others when you are stuck in the bathroom in the middle of the night, changing that 'blessed' pouch. Been there, done that (more often than we care to remember), haven't got the tee shirt, but then again, who needs everything?

Tony Roberts

*Thank you for all your letters, we do enjoy reading them.
Please keep them coming. ED.*



Editing Team
Celia Waters,
Jo Mckenzie, Gill Herbert

Poets Corner...

The Stoma

Today this thing was given birth,
A cherry coloured fleshy blob,
It's a stoma said the nurse
A stoma I blurted in reply,
What's one of them!

It's not the prettiest of things,
But its life, of that I am sure,
It lays there quiet and a sleep,
Two or three days have passed
With out a sign of life about.

Then at last it springs to life,
First a cough and then a squeak.
Then into action it does creep.
Life's wastes at random times,
Come rushing down the line
It tests your patience ever day,
Like a baby it has demands.
Wash wipe and dry today.
And then off we go again
Some time if it's been good,
You take it out for a change.
Give it a bath and some air,
But beware, keep this.
It can plays up from
time to time.

Life must go on, me with it
Good time and bad,
that's a fact
Even when you are
out and about
It will try to embarrass you
With a sudden burst of sound

Still time moves on, it and me
Friends of sort I would agree
We go everywhere together
Because without my friend
I would not be and so the
end of me

So my friend please
remember this,
Your stoma is a friend for life.
Short term< long term, long
term makes no odds.
Treat it with kindness and
loving care
For today it's your life
that its has saved

Douglas

When Cancer Came Knocking

I remember the day cancer
came knocking
I asked fear to answer the door
but he was afraid of the mighty
bully, so Anxiety stood by his
side. They peered and peered as
the Cancer knocked louder.

I thought they were going to
hide. Let's ask Pride to get the
door but Fear kept pulling him
back and Anxiety wept like a
little child who was having a
mild attack.

I am calling on Dignity to
answer the door as Cancer
knocked louder and louder but
Fear kept weeping and wailing
and Anxiety had another attack.
I finally called on Strength to
answer the door and he looked
Cancer straight in the eye.

I must ask you to leave said
Strength and the bully seemed to
shriveled and die. Anxiety and
Fear also left but Compassion was
now at the door. Kindness and
Love stood with Compassion and
they waved goodbye to Anxiety
and Fear forever. Cancer the
mighty bully was gone.

Taken from Internet site
'Living with a Colostomy'

by Terry
Sent in by Terry Wood

Sleepless Nights

Here I am, awake again
I just cannot sleep
My mind it is a wonderful thing
It stores up thoughts all day long
Then when I want to rest
It decides what is best.
Wake up wake up I hear it shout,
What about the day just gone
Good or bad make no difference.
I try my best to clear my brain
Cause all I want to do is sleep

Pictures flash across the screen
Inside my head sight and
sounds
From every angle can be heard
Who put these thought there?
I can't remember did I?
Or someone else
Is it guilt or do I have doubts,
Free thoughts or imagination.
I just do not know.
They lead me through a maze
That makes no sense at all to me
Switch off! Switch off!
I shout aloud,
All I want is some peace

The problems of this
day just gone
Simple things, stirred
up by worries
I try so hard to contain
my thoughts
But still they rumble on
In and out they go.
Through the caverns of my mind,
Touching a nerve or two
along the way.
Just to make sure that
I am awake.
My brain is at bursting point
I cannot take another thought.

Where has it all come from?
Its your concussion I hear
you say
Why now not earlier in the day
When I was wide awake
Till at last silence falls
Over this troubled mind of mine
Enter now the black of night
And whisper silence falls about
Quiet sleep comes on at last
And I am at peace again....

Douglas 24/9/2004



Making the trip...Audrey's Story

Dear Colostomy Association...

As a Colostomate I thought I would write and tell you about my trip to New Zealand, I am a disabled pensioner and have several conditions as well as a colostomy.

My son lives in New Zealand and I hadn't seen him for over 3 years; so I decided to go there on my own to visit him, the journey there was long but I was met with a wheelchair at Pinarg and Kuala Lumpur and taken to my next flight. I had worried about my Colostomy working overtime but I needn't have, I didn't eat too much the day before I went; but as I am diabetic I had to eat something and I took 2 Imodium on leaving home.

The whole journey went without any problems and I had three weeks of glorious sunshine and visited some amazing places.

The journey back was different as there was a lot of turbulence and I also stayed overnight in a hotel.

Kuala Lumpur to Heathrow was 13 hours and I did the same as before pre flight, I was met with a wheelchair off the plane and taken to the car which was to take me home; I was so proud of myself and I have had the most wonderful adventure.

Please tell your readers, so if anyone is going on a long journey not to fear the worst, I was given a seat by the toilet on each journey on the plane and was looked after amazingly well.

Above photo shows my son and myself at NataKare Rangers Auckland New Zealand.

I read your Magazine Tidings regularly and love the poems, and would also like to hope my letter will give inspiration to any disabled and elderly Colostomtes.

Audrey Porter

Notice Board

Chester Support Group

Date: 5th April meeting at the Cheshire View Plough Lane Christleton.

For details contact:
Dave Burgham on 01244 310461
or Ernie Hulme on 01782 324441.

Date: 26th April meeting at Ellesmere Port Boat Museum. 1.30 to 6 pm.

Date: 5th April meeting at the North Staffs Outlook Group have an Exhibition at the Stop Inn A34 Cross Heath Newcastle Staffs from 1.30 pm to 4.30 pm

Further info on all the above contact Ernie Hulme on 01782 324441 or 07973 865743

A Big Thank You

Margot Loftus from the Borders wrote:

Sally Gollock is retiring in March. As a Stoma Care Nurse her dedication and care to all patients (many times out of working hours) has been much appreciated.

I'm sure every one under Sally's care will be very sad to lose her.

We wish her a very long and happy retirement.

Sheffield Stoma Support Group Quaker Meeting House, Sheffield

Tuesday 11 April 2006 at 2.30pm
Subject: Diet/Nutrition

Any queries call Gloria on 0114 2879503

We hope you have enjoyed the new look edition of Tidings and look forward to bringing you the next Edition

We are always trying to improve your Magazine and welcome your feedback.

Tidings is your Magazine

If you have a story, poem, article, letter or any other item you would like to be included, please send them to The Editor along with any relevant photos or pictures and we will do our best to include them!

Don't forget to supply us with your name, address and phone number.

We look forward to hearing from you!

Donations

Should you wish to make a donation 'however small' contributing to the cost of producing Tidings.

**Please send to:
Colostomy Association
15 Station Road Reading
Berkshire RG1 1LG**

Useful Contacts

- **Macmillan Cancer Relief Information line**
0845 601 6161
- **ia (The Ileostomy and Internal Pouch Support Group)**
0800 018 4724 (free phone)
- **Urostomy Association**
0870 770 7931
- **National Association for Colitis and Crohn's Disease (NACC)**
0845 130 2233
- **National Advisory Services For Parents of Children with a Stoma**
01560 322 024
- **National Key Scheme (NKS) From RADAR**
Please write to;
RADAR, Unit 12,
City Forum, 250 City Road, London EC1V 8AF

For a National Key Guide and Toilet Key Send a cheque for £13.50 (incl p&p) Stating that you have a Disability/Colostomy

For just a key send a cheque for £3.50 (incl p&p) or contact your local Council.



Tidings

Dedicated to Colostomates and their Carers

The Colostomy Association is a charitable company limited by guarantee (Charity Number pending) that represents the interests of Colostomates and other ostomates. We provide support, reassurance and practical information to anyone who has or is about to have a Colostomy.

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

If you would like to become a FRIEND, please call
Freephone: 0800 5876744 or 0800 328 4257

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