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- Colostomates of the past
- Readers Stories
- Dear Nurse
- Support Groups

and much more...



Tidin

Dedicated to Colostomates and their Carers

Positive progress...A meeting of hearts and minds taking the Colostomy Association forward with your help...



### Meeting of hearts and minds...

The picture on the front cover is of some of the Trustees who came to Cornwall to hold a Trustees meeting. I had broken my ankle at the beginning of June and have been unable to travel, so they all came to me. They also took the opportunity to check out the first prize in our First Birthday Raffle, which is a stay in our four bedroom, holiday flat for the first week of June next year. They wholeheartedly approved!

We had a very relaxed constructive meeting and managed to cover a lot of ground. Ray Goddard has done a stirling job since Celia left to join her husband and family in Dubai at the end of June. Our best wishes go to her and our thanks for seeing the BCA become the Colostomy Association.

The Trustees have had a lot of big decisions to make about the set up of the office, jobs, lease and, most importantly, where the money is coming from to fund all this. Ray has been going into the office, sometimes as often as three times a week. He has made visits to manufacturers, secured sponsorship and is building good relationships with the medical profession, the Stoma companies and other associations. Our heartfelt thanks for being so dedicated to the future of the CA.

Jackie Dudley continues to visit the office once a week as a volunteer helping out wherever she is needed. We love her informative Volunteer Newsletter and her passion for ensuring that any problems receive attention and solutions. Currently she is helping with an improper security search at an airport.

Ernie Hulme has also been in to the office many times. We never are quite sure what the big man from Staffs is going to do next, but we do know that he is a greatly respected member of our team and his experience and good sense of humour keeps us all pulling together and singing from the same hymn sheet. Ed Scott has done fine work on reviewing the latest NHS consultation document and we thank him for helping the CA to put forward their views on this vital issue. Jean Scott has got us all sorted out with the Helpline in her gentle, sensible teachers way. A big thank you to Gill, Jo and Beryl, in the office, who have worked hard to put together the new issue of Tidings, while ensuring that the office continues to run smoothly and efficiently.

I hope that you will enjoy reading this issue of Tidings and continue to support us in our fundraising. Donations are so important to the future of the CA.

Don't forget World Ostomy Day is 7th October, so please make a point of supporting your Stoma Nurses if they are celebrating this great event.

Best wishes to you all,

Sue Hatton

Chairman of Trustees Colostomy Association

#### Update...from Station Road

As Sue has mentioned, in her introduction, there has been a lot going on since the last issue of Tidings. Celia Waters has left to go to Dubai with her family and I would just like to add my own thanks to her for her hard work in setting up the Colostomy Association. If it had not been for Celia this magazine would not have dropped through your letter box.

I am assisting in the running of Station Road and looking at ways in which we can increase our income and cut our costs. We will be looking at all that we do to make sure that we are providing the best service that we can to all of our friends.



With that in mind, you will find a questionnaire in this issue which will enable you to give us your feedback on the magazine and how we can make further improvements. The next issue of Tidings will be even bigger (48 pages) and will include a 'small ads' page.

As in all organisations of this type and size, we always need assistance from skilled helpers. If you think you can help with research or taking articles forward, please contact the office. In particular we would welcome hearing from people working in the NHS who have a stoma or colostomates with medical or legal experience or who are interested in becoming a Trustee.

We are already starting to plan for the next issue of Tidings which should be with you shortly after Christmas. The issue will have a theme of Irrigation and we would be happy to consider any articles / letters/comments which you may wish to submit. Our First Birthday Prize Draw will be taking place on 15th November and I would urge you to phone the office for raffle tickets so you don't miss out on your chance to win one of our great prizes.

The first year of the C.A. has certainly been a very interesting and busy time for us all but I believe that we now have the required building blocks in place and we will now go from strength to strength.

Ray Goddard



On November 15th we shall be celebrating our FIRST BIRTHDAY! To mark the occasion we will be holding a RAFFLE - WITH A DIFFERENCE...A fantastic WIN WIN opportunity for you and the Colostomy Association...

We would like to encourage you to take part ...to help us raise much needed funds that will really make a difference... for you and us



So, Read on...and Good Luck!

#### 1st PRIZE - A Fabulous Luxury Holíday ín Cornwall

A Fabulous Luxury Holíday ín Cornwall , sítuated along the beautíful Helford Ríver by the village of Constantíne.

The apartment sleeps up to seven people in four bedrooms, and is offered between 2nd June 2007 - 9th June 2007.

For more information go to:www.classic.co.uk - Cottage no. 1140 Melyn Goth. Good Luck!

(Courtesy of our Chairman - Sue Hatton)



#### OTHER BRILLIANT PRIZES ... a huge thank you to all those who have supported us.

2nd PRIZE £250 M&S Vouchers Donated by ClíníMed

3rd PRIZE One night accommodation for two Lowndes Hotel, Belgravia, London Champagne on arrival Donated by Carlton Tower Hotels

4th PRIZE Afternoon tea for two at the Dorchester Hotel London Donated by the Dorchester Hotel

5th PRIZE £75 WH Smith Voucher Donated by Lamport and Gilbert

6th PRIZE DVD Player Donated by Salts

7th PRIZE Microsoft Encarta 2006 Donated by Microsoft

8th PRIZE £20 Game voucher Donated by Game 9th PRIZE Vue Cínema Vouchers x4 Donated by Vue Cínemas

10th PRIZE Risk board game - Star Wars edition Donated by the Entertainer

11th PRIZE Microsoft Autoroute 2006 Donated by Microsoft

12th PRIZE Microsoft Office Professional 2003 Donated by Microsoft

13th PRIZE £10 B&Q Voucher Donated by B&Q

14th PRIZE £10 M&S Voucher Donated by M&S

15th PRIZE "School Days to Spitfire" By Dr Gordon Mitchell Donated by Gordon Mitchell Tickets are available NOW from the office. Please contact us if you would like a supply. FREEPHONE 0800 328 4257

They are priced at £1 each and are available in books of ten. Remember, you don't have to buy all the tickets yourself, take them along to your local support group or workplace.





CliniMad"



Lamport — —Gilbert

PS. Raffle tickets must not be sold to/or by those under sixteen

# charty help and raise money to

# Fundraising...Success Stories

As you are probably aware, we have had to become a totally self-funding charity. We rely solely on donations to continue giving support and advice to colostomates up and down the country. Fundraising plays a vital role in the CA and we welcome your comments and ideas. All efforts are greatly appreciated.

Fundraising can be hard work, but keep it simple, accept offers of help and above all - enjoy yourself!

Here are some of our success stories so far...

#### Ruby Wedding Donation

Many thanks to Mr and Mrs Michael Robbins who sent a cheque for £325, which was donated by family and friends in lieu of gifts at their recent Ruby Wedding Anniversary celebrations

#### KSD Summer Party

KSD Decorating of New Milton, Hants recently held their annual summer party. All money raised was donated to the Colostomy Association. We were pleased to receive a cheque for £187.79

#### Granny's Attic

Celia, Jo and Gill (from head office), had a great day out at the Tilehurst show in July. We raised over £111 by selling 'Bric a Brac', cakes and soft drinks.

#### IMS

A big thank you goes to IMS hospital Group Ltd who sent us £210 on behalf of Stoma care Nurses from Portugal who took part in a study conducted by IMS Health earlier this year.

#### SecuriCare

SecuriCare recently held a survey and asked participants to nominate a charity of their choice to receive a donation. One of the two winners chose the Colostomy Association and we received a cheque for  $\pounds 50$  'to assist in the continuation of the invaluable work done by the organisation'.

#### Colostomy Association 1st Birthday

Head Office are planning to hold an open evening in Reading on 15th November 2006 to celebrate the first birthday of the Association. Our special guest will be Glyn Davies, MP, who has kindly offered to draw the winning tickets from the raffle. The event will be an opportunity for friends to meet the staff at head office. some of the Trustees and local volunteers. Many suppliers and manufacturers will also be in attendance, so put the date in your diary now! If you are also planning to celebrate our birthday by holding a special event on this day, please let us know.

#### Recycling

Please continue to support our recycling appeal. If you log on to www.recyclingappeal.com or call 0871 250 50 50 you can order freepost envelopes to recycle printer cartridges and mobile phones on our behalf. We also have a supply of envelopes in the office.

#### Fundraising Ideas -We receive lots of fun ideas on how to raise money...

One we particularly liked was 'Inside out Day' - For on one day you go to work etc wearing one item of clothing inside out, to represent the fact that people have bits of their insides on the outside! Ask people to pay a £1, or whatever they wish, to the cause.

A cheese and wine evening always goes down well. Ask friends and neighbours to 'bring a bottle' and a £5 donation. Supply a selection of cheeses and cheesy nibbles on the night along with a raffle and maybe a quiz. If anyone offers to donate food/raffle prize then say yes!! Contacting local supermarkets etc is always a good idea as the £5 vouchers they may give all add up.

#### Making a real difference -A legacy for the future...

We are grateful for all donations we receive. We use them to help raise the profile of the colostomate and heighten awareness of the symptoms that can lead to a colostomy. As a self-funding charity we will only be able to survive and plan for the future with the support of friends.



By leaving a legacy in your will, you can really make a difference. It's simple to do and will enable others like yourself to live their lives to the full, with the help of the Colostomy Association.

It is important to seek independent professional advice when making or updating a will. There are a few different kinds of gift you can leave in your will; your solicitor will be able to guide you on this. The only details you will need to include are our full charity name, address and charity number:

#### Colostomy Association 15 Station Road Reading RG1 1LG Registered Charity No. 1113471

Scottish law varies, please consult your financial advisor.

You can also make a donation to the Colostomy Association in memory of a loved one. This is a positive way to remember someone and will contribute to our future success in helping our 17,000 friends with reassurance and friendship.

# "Because life is for living"

(FREESTYLE® CURVEX® USER)

FreeStyle Curvex is designed to give you the freedom to live life to the full and is ideal if you have any leaks or a slightly recessed stoma, even if it is only on one side, or if you have creases around the stoma site.

FreeStyle Curvex, which is available in both closed and drainable versions, could be an effective alternative to pastes and washers and is also suitable for hernias.

With its unique Hyperflex<sup>®</sup> 3-D contoured flange, which gently moulds into the body shape, you'll be confident of a secure, comfortable, leak free fit giving you the confidence to live life to the full.

If you want to experience the Curvex confidence, contact us for a free sample.



For a free sample of FreeStyle Curvex Closed or Drainable please complete the coupon and return it to: **Chinille A Let., FREEDOST, High Wysenbe, Ender HP 24 00%** (NO STAM P. RBOUIRED) or call the Welland Caretine on OSOO 585 125.

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Dear Readers...



Eleven years ago, I had a colostomy due to cancer. I had been visiting my GP for fifteen months, before the cancer was finally díagnosed. Everyone should know how important it is not to ignore embarrassing symptoms and if necessary seek a second opinion. After the operation I needed five weeks of radiotherapy and chemotherapy. Then I developed an abscess and had to be readmitted to hospítal.

I am in my sixties now and live in the Northampton area, having moved here from London twenty-four years ago. When I was younger I was employed in retail - in a baker's shop, a department store and a dry cleaning firm. When the children grew up I went back to work in the catering business. I am divorced now and live on my own, but my three children and five grandchildren often vísít. I enjoy most kinds of music and eating out.

I would like to correspond or talk over the phone to someone else who has a stoma with the possibility of meeting up if we have the same ideas about making the most out of life. I would also be interested in attending a support group, where people with stomas meet for a "cup of tea and a chat" - to share experiences and exchange tips on coping with a colostomy. However I'm not sure whether there is such a group in my area.

#### Patricia Hayman

Jean Scott, our contact volunteer in Northampton, is one of the Out of Hours Helpline team. She has a stoma herself and is happy to speak to colostomates over the phone or visit them at home. If you would like to talk to Jean, Head Office will pass on her number. Jean also tells us that she is keen to start up a support group in the area and would like to hear from anyone who would be interested in coming along.

Need someone to talk to ...

Would you like to share experiences with another person who has a stoma?

This could be by letter, over the phone or by e-mail

If so send us a brief description of yourself: age interests etc.

Tidings won't publish your name if you don't want us to; we'll simply forward any replies to you then it's up to you to decide if you want to make contact.



### World Ostomy Day...

'The aim of World Ostomy Day is to bring to the attention of the public and global community the importance of improving the rehabilitation of ostomates'

International Ostomy Association

The theme this year is 'Living life to the full' and events will take place all around the world on or around 7th October 2006.

#### Nottingham

World Ostomy Day Service Sunday 8th October at 3.00pm St. Martin's Church, Trevose Gardens, Sherwood, Nottingham. This service is for all people with stomas, their families and friends as well as stoma nurses and all those who care for stoma patients. It is an opportunity to give thanks for our own recovery from surgery and for the skills of the doctors and nurses, and to pray for ourselves as well as others. All are welcome to this non-denominational service. Parking beside the church.

Disabled access and toilet available Refreshments after the service

#### Brístol

Bristol ostomates self support Group (BOSS) When: 6/10/06 10am-4pm Where: The Keep, Arnos Manor Hotel, 470 Bath Road, Arnos Vale, Bristol Live music, refreshments, exhibition of stoma care products, clothing advice available Contact Maurice Cox 01179 358949 Christina Hammond 01179 075326

#### Newquay

The *ia*, UA and CA are celebrating World Ostomy Day in the Hotel Rivira in Newquay on Saturday 7th October 2006. There will be entertainment, afternoon tea and a raffle in the Ballroom. The Hotel is situated at the Quintrell Downs end of Newquay.

### **Confidence® Comfort**

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Undamaged skin is essential for the normal use of a pouch, and adaptation to life with a stoma depends largely on healthy skin. That's why Salts Healthcare designed Confidence Comfort, a skin-friendly pouch that's kind and gentle to the skin.

And we're delighted to be the first ostomy product manufacturen to be accredited by the British Skin Foundation for our research and development of comfortable, secure and skin-friendly pouch adhesives.

So remember, you don't have to put up with sore or initiated skin any longer: Simply call the Freephone number below and ask for your free sample of Confidence Comfort. It may be the last free sample you ever have to ask for again.

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### Never say 'No'...an Ostomates incredible New Year Wedding Trip

We had made great plans for December 2005. Things were changing in our family. Samuel, our youngest child and only son, had been studying in the U.S.A. for a Master's Degree in American History and his graduation was set for December 17th. Naturally we wanted to be there for this occasion. However, more importantly, whilst in America he had met and fallen in love with a most beautiful and gentle young lady named Laura. She lived in her home city of Norman, Oklahoma and a wedding date had been set for New Year's Eve. She had stayed with us for four months during the summer of 2005, while Samuel continued some research in this country. During that time we grew to love her very much. Her parents and one of her brothers visited us and we found ourselves to be most compatible as two families. We had so much in common. Our choices, priorities and faith were the same. We had even married on exactly the same day as Laura's parents in 1972.

Yes, we were very happy with this match and began to make our plans. We arranged to fly to Atlanta on December 15th in order to attend the graduation. Samuel would then fly to Oklahoma in order to help finalise wedding plans. We would have a few days holiday at the Grand Canyon then fly to Oklahoma, spend Christmas with Laura's family and prepare for the Wedding on December 31st. Our two daughters, plus one fiancé would join us over Christmas and stay on for the wedding. Other friends and family were also flying out to share this happy wedding day with us. We eagerly looked forward to a wonderful time.

However our plans do not always work out as we anticipate. I had worked hard all year at my business and put in many extra hours. I felt terrible some days and some of my patients were beginning to notice and tell me how awful I looked. I put it down to exhaustion and kept willing myself on through each week, counting the days until we could depart for America. Things became worse as I began to feel pain in my abdomen from time to time and I would suddenly vomit.

For a number of years I had been a patient of Professor Hawkey, a gastroenterologist at the Queen's Medical Centre, Nottingham. I arranged an appointment with him and waited. However, I was getting steadily worse and through the night of November 19th I began to vomit and could not stop. By 7.00am I was so weak and ill that my husband took me to A&E where I was admitted. I was transferred to a medical ward and over the next week and a half I underwent a number of invasive, diagnostic tests. Eventually I had a colonoscopy and it was discovered that I had cancer of the large bowel. I had both a primary and a secondary tumour and this was only 18 days before we were due to fly out for Samuel's graduation. I coped with the thought of cancer with a great peace and no sense of anger at all. However, as I explained to the medical team that I had plans to attend my son's wedding, my eyes filled and I cried at the thought of not being there. I explained that I was more than willing to miss the graduation and cancel our Christmas plans, but I so desperately wanted to be at my son's wedding.

Immediately the team rallied in understanding and sympathy and a surgeon was booked to come and discuss the necessary surgery with me. When Mr Williamson, the surgeon, arrived at my bedside he already knew about the wedding and the need for urgent action if I was going to attend. He explained that due to the nature of my condition it was necessary to act quickly. The entire large bowel had to be removed. He would construct an ileostomy and I would have to adapt to a stoma bag. Furthermore he told me that if all went well and I had no complications then I might, just possibly, be well enough to make the flight. I promised total co-operation and that I would "be good and rest" (a definite first for me!) The surgery date

was set for the morning of Saturday 3rd December and I was the first on the list. I was so deeply grateful to him for being willing to operate so soon and at a weekend. My husband, family and friends set to in prayer that all would go well and I laid the whole matter down at God's throne.

The surgery was wonderfully successful. I did "do as I was told". It was not many days before I was back on my feet and was learning to live with my stoma. I was discharged from hospital and went home with a solid determination that I was going to go to Samuel's wedding even if my husband had to wheel me there in a Sainsbury's trolley! The word was sent out – "no visitors yet'" - and I rested and slept and recovered well.

During all of this time the support and encouragement that I received from the hospital staff, particularly the stoma nurses, was absolutely wonderful. I could not have had better treatment if I had paid for it. Mr Williamson produced a letter for the airport security staff explaining that I was carrying necessary sharps and medical supplies, that I had recently undergone major surgery and that I needed their support. Jeanne Watts, the stoma nurse, checked me out just before Christmas. My skin surrounding the stoma had become very sore and was beginning to break down. She taught me how to treat and care for this and then fitted me with more suitable appliances. I have had no trouble since that day. Furthermore she contacted a stoma nurse in Oklahoma and explained my position. I was given this nurse's name and phone number as she would help me if I got into any stomadifficulty whilst in America. Jeanne also gave me a phone number at the Queen's Medical Centre which I could use in the event of needing her advice or help.

"If we set all this up," she said, "you probably won't need it but if we don't make emergency plans you may be left without help and we don't want that."

How grateful I was and still am for the care of our superb stoma nurses. As Christmas approached I resisted all temptation to visit friends but on Christmas Eve I so much longed to go to our Midnight Church service. With the help of my constantly encouraging husband we went together as is our normal custom. When our Pastor said how good it was to have Joy with us again everyone jumped to their feet and clapped and cheered! Not very reverent one might think, but I felt overwhelmed with the love of my friends and of God. They prayed that I would have supernatural strength to make the journey to Oklahoma and back again.

And so it was that on 27th December 2005, at only 24 days post-operative, I flew to Dallas, Texas and then had a six hour drive (because we took a wrong turning!) to reach Oklahoma where my other family and friends were waiting. It was a long and tiring journey but not impossible, or without help. We were travelling with two friends and my sister in law. Concerned for my comfort, my husband, David, had booked me into Business Class, while he travelled in Economy. When we arrived at the airport and checked in, the stewardess sent for a porter and wheelchair. The Business class Departure Lounge was available to me and she kindly extended that facility to David also.

When the time came for us to board we explained to the Boarding Pass Steward why we were seated separately and he immediately upgraded David to be seated next to me and at no extra charge. We were so grateful both to B.A. and to God for their care! I enjoyed the flight and had no pain or discomfort whatever. I was injecting daily with heparin to prevent DVT, as prescribed by my GP. Once settled I slept some of the way. At other times I walked around a little and found that managing my stoma bag was absolutely no different to being on the ground. I had changed to a fresh bag and flange before flying and also had extra supplies with me in case an emergency bag change was necessary. However the entire flight proved to be trouble free, as did the following six hour drive.

I was REALLY tired by this time but, in spite of having hired a comfortable eight-seater people-mover, I just could not sleep. We all needed a couple of "comfort" breaks along the way and that was sufficient for me too. After needlessly trailing around two sides of an enormous triangle as we crossed Texas, we finally entered Oklahoma State on our way to Laura's home town of Norman. The journey took 23 hours, determination and organisation. I needed help, encouragement and support. I felt exhausted at the end and willingly admit that without all that help, both mortal and Immortal, I could not have done it. But I did do it.

As ostomates we do not need to worry



about travel. Help is out there if we use it. Fear that we might not make it, or pride that prevents us from asking for help, will keep us from enjoying a normal and fulfiled life. I so much want to encourage every reader of this story to be similarly determined to overcome the difficulties that are common to us all and get out there and enjoy the huge and beautiful world that we live in.

And the wedding? Yes it was a most wonderful, happy day for two families and all of their friends. I wouldn't have missed it for the world and, thanks to so many people, not just doing their jobs, but going the second mile for me, I was able to see my Samuel married to his Lovely Laura.

Joy Negus, Stapleford, Nottingham.

#### information

### Waste Disposal for Colostomates...

With the increasing number of Councils, all over the country, announcing that household waste will only be collected fortnightly, a number of readers have telephoned asking for our support in approaching their local council to have this decision reversed.

The worry seems to be that the bin will become "smelly" and attract flies and vermin. This certainly could happen if your council only provides black sacks and not the rigid "wheelie" bins that have a lid to enclose all the rubbish. We know that you worry about the odour emitting from the bins and bags in the very hot weather and that they could become an ideal habitat for fly infestation

We also know that many of you have written in protest on this matter and we, as your Association, have also approached councils on your behalf.

As always, we are told by the Councils, it is a matter of cost – and saving money by collecting household waste fortnightly allows the councils to direct the savings into other services. I suspect that councils are not going to change their minds and revert to weekly household waste collection.

An ideal solution for a member who is able to wear a one piece closed bag is the flushable bag. This eliminates the need to place a soiled bag in the bin as the liner is flushed away in the toilet. However, for those that are not able to use this product, the problem of disposal needs to be tackled.

Cutting the bottom off a colostomy bag and emptying the contents into the toilet, will help cut down the smell. I do know that some members find this difficult to face and so throw away the full bag. It is therefore even more important to ensure that these are well contained in the disposal bags, then wrapped in newspaper and placed in a carrier bag before being placed in the bin. One very good tip is to use cling film to wrap the disposal bag - this will ensure no odour escapes.

If you have access to a computer, www.freshbin.co.uk is a web site that tells about a bin freshener. This hangs inside the bin and emits a citrus fragrance which also contains Citronella oil and is released every time the lid is raised. These bin fresheners may be available from local hardware stores and newsagents. Alternatively a spray bottle, filled with a diluted antiseptic liquid, can be used at regular intervals to spray the interior of your bin. This will help freshen the bin itself and kill lingering odours.

> Waste Disposal taking up the challenge...

We know that many of our members have written in protest on this matter and we, as your Association, have also approached councils on your behalf

Although drainable bags are primarily designed for ileostomists, some colostomates also use them. They find that, as these can be emptied while still in place, they do not need to dispose of so many used bags. Also the appliance is empty when it is removed and placed in the dustbin. However, whether a drainable appliance is suitable for an individual colostomate depends on the consistency of the output from the stoma; for some it may be difficult to empty through the narrow opening at the bottom of the bag.

Some councils (not all) will collect Clinical Waste from your home. This could mean used colostomy bags. Clinical waste collections are usually (not always) free of charge to householders who need to dispose of medical waste. Collections are normally arranged as a result of a referral by a hospital, health visitor, G.P., district nurse or home care assistant. This would mean that your "Clinical waste" would not be placed with your normal refuse. It should be stored in the special yellow clinical waste bags or box prior to collection. These are usually provided free of charge for domestic customers.

The clinical waste collections are sometimes carried out once a week by a separate collection crew to your normal household collections as the waste is taken directly to the "Energy from Waste Plant" (EFW) for safe disposal. Call your council to ask if you can have this method of disposal and to find out more information. I do hope that this article will help take away some of the concerns that you may have about this dilemma. It is a common problem to all of us who have to dispose of used colostomy bags.

If members have any ideas that will help us out of this predicament, please contact the office and we shall be pleased to print your ideas in the next Tidings.

by Jackie Dudley Volunteer - Berkshire

### New...Small Ads

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

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

ONLY from Coloplast

TAK

TWO filters for **enhanced** airflow

# Confidence two gether

### Do you have a problem \ with ballooning or odour?

Then the **Assura Inspire** with **Dual Filter** may be just what you need

Two advanced filters instead of one which means:

Increased airflow to counter ballooning

Twice the filter capacity for improved odour control

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or visit our website www.coloplast.co.uk

### **Henrí Matísse** French Painter · Sculptor · Graphic Artíst · Designer

Colour for Matisse was like music, and he often said that he heard 'colours sing'. He worked to transcribe the hidden harmonies the colours and emotions inside the object. His aim was to 'retain only what cannot be seen'. His vast artistic legacy illustrates that Matisse succeeded in achieving this extremely subtle and challenging goal.

Henri Matisse was born on New Years Eve 1869 in the Picardy region of Northern France. He planned on a legal career and studied law, then worked as a clerk in a solicitor's office. In 1890, at the age of 21, Matisse became seriously ill with an attack of appendicitis. During convalescence he began painting and discovered his love of art and this became a lifelong passion. A year later he gave up law and moved to Paris to study art formally.

Matisse's early teachers were relatively conservative and when he began to experiment with contemporary art, especially that of the impressionists, he earned a reputation as a rebellious member of his studio classes.

His daughter, Marguerite, was born in 1894, although he did not marry her mother, Amelie Paraere, until 1898. His sons, Jean and Pierre, followed in 1899 and 1900.

By 1905 Matisse had produced some of the boldest colour images ever created, including a striking picture of his wife, entitled Green Stripe, this referred to a broad stroke of brilliant green that defines Mdme. Matisse's brow and nose. In this year Matisse exhibited this and similar works along with those of his artist companions including Andre Derain and Maurice de Vlaminck at the Salon d'Automne. The group were dubbed Les Fauves (the wild beasts) because of their use of intensely vivid colours, with Matisse being generally regarded as the leader. Soon he acquired his first important patrons and was now freed from financial worries and could afford to travel. His growing reputation also attracted many pupils to the art school he ran in Paris from 1907-1911.

From 1906 he was a friend, as well as rival, of the younger Picasso, to whom he is often compared. A key difference between them is that Matisse drew and painted from nature, while Picasso was much more inclined to work from imagination. The subjects painted most frequently by both artists were women and still life, with Matisse more likely to place his figures in fully realized interiors. One thing they had in common is that they both found African Sculpture an exciting art form at this time.

In 1917 Matisse and his family left Paris and settled along the Riviera, mainly at Nice and also at Vence. Here he spent fifteen straight years painting. The luxuriously sensual works he painted there, still life, tropical fruits and flowers, were influenced by the strong sun and rich colours of the south.

When he was 72 he had two major operations for duodenal cancer. which resulted in a colostomy. Although Matisse was now confined to bed or a wheelchair, he worked until the end of his life and one of his greatest and most original works was created between 1949 and 1951, when he was in his eighties. This is the Chapel of the Rosary at Vence, a gift of thanksgiving for the woman who nursed him after his operations and later became a nun at this Dominican convent. Matisse designed every detail, including the priests' vestments. The stained glass windows show his familiar love of colour: the walls feature murals of

H. matisse

pure white ceramic tiles decorated with black line drawings of inspired simplicity. While the simple white exterior has drawn mixed reviews from casual observers, many regard it as one of the great religious structures of the 20th century. Matisse himself regarded the chapel as his 'masterpiece'. He was not a believer himself but created one of the most moving religious buildings of the 20th century and expressed what he called 'the nearly religious feeling I have for life'.

When Matisse was too weak to stand at an easel and paint, he created brightly coloured paper cut-out artwork in bed: one of his most famous being 'Blue Nude'. The colours he used in his cut-outs were often so strong that his doctor advised him to wear dark glasses! They must rank among the most joyous works ever created by an artist in old age.

Matisse died in Nice on November 3rd 1954, aged 84 years. Unlike many artists, he was internationally popular during his lifetime, enjoying the favour of collectors, art critics and the younger generation of artists. He never attempted to express the troubled times through which he lived in his work. He once wrote. 'What I dream of is an art of balance. of purity and serenity devoid of troubling or disturbing subjectmatter...like a comforting influence, a mental balm - something like a good armchair in which one rests from physical fatigue.'



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### Reminiscences...

Mrs Willans kindly agreed to a telephone interview. She told me about her life and how she has coped with her colostomy for the last fifty years...

### *Tell me about your life before you had a colostomy.*

I was born in Llanwrin, Mid Wales, in 1910. When I was eight the family moved to Dinas Mawddwy: to a hill farm on the banks of the River Dovey. Up until then I'd only ever spoken English, but at my new school all subjects were taught in Welsh. Nevertheless, in the eleven-plus, I was top girl in maths for the whole of North Wales and was awarded a prize of five pounds – this was the first time I had ever seen a cheque. The secondary school was at Machynlleth, eight miles away, and before catching the train in the morning I would often milk a cow.

My ambition was to be a teacher and I was accepted by Bangor Normal College. In the 1930's life on campus was very different from today: female students lived in Bangor and male students across the Menai Straits on the island of Angelsey. Once I was reprimanded for entertaining a man in my room. When I protested that it was my brother, they said, 'Wouldn't they all like to have a brother!'

My first job was in Liverpool, then after a year I moved down to London to teach in the East End. I hadn't been there very long when the headmistress said, 'All Welsh people can sing. You can take the children for music on Monday.' This was two classes together, close on a hundred pupils, all sitting cross-legged in the main hall. The only problem was I couldn't play the piano!



'My husband had a great part in my getting better.' Mr & Mrs J.W.Willans in July 1966, ten years after her colostomy operation.

Although I enjoyed my work in the East End, after four years it was time for a change. I got a job in Belgium teaching at The British School in Ypres. Two years later I was home on a week's leave, when I received a message telling me not to come back: the school had closed down, it was 1939, the start of the war.

I returned to teaching in London, but not for long; children were being evacuated from the East End, so I was sent with them to Barnack near Peterborough. I would often look over the hedge at Spitfires on the runway at Wittering and wonder if we were any safer here. We arrived in September; by December all the other teachers who couldn't get used to country life had returned to London. I was now left in charge of all the girls billeted in the fourteen scattered villages. I bought a bike.

In 1940 I was to accompany evacuated children on ships crossing the Atlantic, but, after the sinking of "The City of Benares" when 77 children drowned, evacuation abroad was abandoned. I sailed for the Falklands instead. It was on this 8,000 mile voyage that I met Lieutenant J.W. Willans, Royal Navy, on his way to a posting in the Falklands. He was the man who was to become my husband – although he didn't know it at the time!

During the three years I was teaching on the Falkland Islands we were once more evacuated - this time to Goose Green. When I arrived with the children we doubled the population! We were there for ten months and the locals were amazed to discover that the London teacher was able to milk a cow, and help with the sheep shearing and dipping. Some of my friends in the Falklands still write to me now, but each Christmas the number of cards decreases. I suspect I may have outlived some of my expupils.

It was at the end of 1944 that I returned to Britain, in an Atlantic convoy dodging the U-boats. We were aboard a cargo ship, adapted to carry twelve passengers; her consignment was corned beef to feed a hungry U.K.

Lieutenant Willans and I got married after the war in September 1945. We moved to Somerset where I began working as a supply teacher.

### When did you have your colostomy?

It was 1956. I had a polyp which they told me might develop into cancer. I was in hospital for three weeks before they did the operation – said I was too tense. When a letter arrived from my sister, who was looking after our eight year old son, I thought about how he must be missing his Mum and cried for the first time. The ward sister was kind: she drew the curtains round the bed, waited till I was all cried out, then said, 'Your operation's tomorrow.' In theatre, the operating table was covered with seven inches of foam rubber to protect my weak spine. I woke up with a colostomy, which protruded an inch from my skin, and an incision held together by seventeen stitches. You can still see the scar today - not like the one I had after an operation for colon cancer forty five years later, which has now faded. They told me there was no chance of having a reversal: they had removed my rectum and anus and sewed me up with another ten stitches. For three days and nights the nursing staff came every twenty minutes to lift me up and turn me over in bed. Four weeks later I was transferred to a nursing home in Bournemouth; the one in Bristol refused to take me because nobody knew what a colostomy was.

When I was discharged home I was told to avoid oranges and onions! Apart from this I refused to change my diet. I didn't want to feel different. They also suggested a small sherry before lunch to stimulate the appetite – advice I am still following fifty years later.

### *How did you manage when you got home?*

In those days we didn't have colostomy bags. Cellulose wadding was cut into seven inch squares and placed over the stoma with a layer of mesh to keep it away from the skin. A covering of supposedly waterproof, oiled silk was placed over the top, to prevent staining the clothes; I remember the colour: it was a shiny green. All this was kept on by strips of material wound round the body and fastened with large safety pins. This method was very unsatisfactory. Then I heard from another lady with a stoma and she told me what to do: 'Buy a suspender belt that's quite tight and put the wadding underneath it. When you attach the suspenders to your stockings, this will pull it down and keep the dressing in place.'

### *How did you feel about having a colostomy?*

It took me a long time before I would look at it. Then I decided that it was a nuisance, but very important. My husband was very supportive. We didn't want our son to know the word colostomy or use it at school. He told his friends that his Mother had been in hospital for a miraculous operation, and the surgeons had put in a new valve. Well it was true. At home we called my stoma Rodger – Rodger, the lodger, the unwelcome visitor. Apart from that I never talked to anyone about my colostomy.

### *How long did it take you to recover?*

It's hard to remember now, but at first I was very tired. I used to pace myself, by doing jobs around the house for twenty minutes, then sitting down for twenty minutes and so on through the day. Before I went into hospital I had been offered a post as a head teacher, but the surgeon had said it would be two years before I was able to go back to work and the school wasn't able to keep the job open that long. However the following year I was back teaching, just a few hours at first, then gradually increasing the number of lessons until I was doing a half day.

### *Did your colostomy cause any problems at school?*

The headmaster knew of course but no one else. When it made unexpected noises during lessons I used to bend down to pick up an imaginary piece of chalk. When I was using the wadding and suspender belt I used to have to go to the toilet every hour to check on it. I used seven layers of wadding and removed the inner one when it got soiled.

#### You must have been very relieved when they produced colostomy bags.

Well, I didn't trust them at first. The glue on the flange was patchy and they didn't always stick all the way round. I would always take a supply of the wadding I'd been used to, when I went out – just in case.

## *How do you feel that a colostomy has affected your life?*

At first I felt I had changed from being a wife and a mother to a granny; I was only forty six. I didn't feel secure and I stopped going out to social activities. Although I still went to school concerts where there was singing, I stopped going to church services in case my stoma made a noise during the sermon. I gained more confidence when I went back to work. In the 1960's it was I who persuaded my husband and son that we should go abroad for our holidays.

# What do you think about modern colostomy appliances?

The bag I use today is very good, so much easier and reliable. For fortyfive years no one else ever looked after my stoma. But when I went into hospital for an operation in 2001, I said to the consultant, 'I can't do this anymore.' So now the carers at the home, where I live, change my bag. They are very good and compete to see who can do it the fastest. I would like to take this opportunity to say how very kind all the staff are here at The Methodist Care Home in Bath.

#### Have you any advice to pass on to other people with colostomies?

Don't be downhearted. There will be bad days, but they won't last. Oh! and I remember, fifty years ago, asking my doctor, 'Is having a colostomy going to shorten my life?' His answer was: 'Probably by ten years.' I am now ninety-six.

Thank you for sharing your story with us, Mrs Willans. It has been fascinating to hear about your life and what it was like for people with stomas in the fifties and sixties. It has made me realise how lucky we are to have modern stoma appliances. I am sure our readers will agree.

Interview by Rosemary Brierley The Curíous Incídent... a wheelbarrow...a broken ankle and a Weddíng...

I can clearly remember, in the first weekend of June, trying to get myself organised to go to Devon for the Hen weekend of my middle daughter, Jo. I had sourced this amazing stately home for seventeen girls to stay in and was taking lasagnes, puds and cake. Off I went, leaving husband, ninety year old father, lettings and change-overs. I remember praying, "Dear God, please help me, I have too much on my plate, too much to think about and I don't seem to be doing anything very well."

The weekend was a huge success. The weather and the lasagnes were brilliant. We all swam, played tennis, silly games and the bride to be had the best time. When all the Hens left, my father came to join me and we had two peaceful days before visiting great family friends on the return journey. They were in their garden and being the bargain hunter that I am, I asked if we could have some of their Hostas, Hellibores and Irises for a shady walk by the stream near our house that my father has been developing.

Liz and Ian gladly dug up huge clumps of plants. Pa and I crammed them into the car, diverted to St Mawes for me to give a talk on 'An Embarrassing Illness: Life with a Colostomy!' to the Women's Institute. We arrived home at 10pm. My husband, Neil, had been warned to get three wheelbarrows at the ready and I off loaded and watered all the plants before climbing into bed. The following morning, Neil had to leave to go to Leicester for a Meeting. The alarm went off at 5am. At 5.30 I was in gardening gear and Wellington boots, as happy as a pig in poo, stomping up and down, planting all my plunder, determined to get it all done before my father awoke.

It was a fabulous morning. I waded into the stream to get fresh water to douse all the Hostas, dug huge holes, loaded in compost and water and was in heaven until the last wheel barrow. It was 7am. I was tired, the wheel barrow was very heavy and I knew I shouldn't have attempted to try to manhandle it across the field to the stream. This sensible little voice inside my head said, "Don't do it." The impetuous voice told me not to be such a wus and get on with it. I left the gravel of our drive, reached the bank of dewy grass, the wheelbarrow lurched to the right and I heard this 'crack' as I went flat on my back, my right ankle bent underneath me. I distinctly remember saying as I lay looking at the sky, "Dear God, I know I asked for help, but I'm not sure this is quite what I meant."

Five minutes later my wonderful neighbours had heard my pitiful wails for help, the ambulance had been called, a teddy tucked into my overnight bag and instructions left for my father, still sleeping peacefully, and for the new tenants, who were not expecting both host and hostess to be otherwise engaged!

The last time I had been in hospital was eight years ago when I had a blockage in my bowel, because I scoffed a crumpet too fast! (Be warned, those lovely scrumptious foods, that we long for when we are ill, do sometimes rebel and give us



hell if we don't masticate them zillions of times before swallowing!) I was told I had a 'Spectacular break'! Not only had I fractured my ankle in two places, but I had dislocated the joint and torn ligaments. I never do things by halves! I was told the waiting list for operating was full and that the



general rule for operating was either six hours after the break, or six days; needless to say, I waited six days before the ankle was pinned.

During the six days I was moved to four different wards, which meant having to cope with four different loos with a colostomy and a broken leg! The nurses were generally great, really intrigued with how I coped none of them knew about irrigating. It was a great learning curve for all of us. The commodes were grim and the bed pans even worse - what a palaver! I am sure we could all tell some horrific stories about our experiences, but in a way I was thankful that the painkillers did a good bunging up job, because at least I was in control of my bowels - the last thing I wanted was a mucky plaster!

It is now three months since the 'incident'. The wedding was fantastic, absolutely perfect, and I must have been the most laid back mother of the bride as I could do nothing. On the morning of the wedding I sat on my bed with my three lovely daughters, as they got ready and I revelled in being part of their excitement. My new son-in-law said in his speech that he now had a mother-in-law who was well and truly plastered!

I am now out of plaster and awaiting the arrival of five Trustees who are travelling down to Cornwall for a long overdue meeting. If Mohammed can't come to the mountain, the mountain is coming to Cornwall! One of my friends commented, "God knew you needed a good break, Sue." I have certainly had one!

Image:	Ź	Tidings		readers feedback questionnai
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3. Which articles in Tidings do you read?			
Article	Always	Sometimes	Never
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4. Which articles in Tidings do you find the r	nost interesting?		
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5. Do you share your Tidings magazine with anybody? If so, how many people?

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6. What other types of articles would you like to see in Tidings in the future?

(Please provide details.)

7. Are there any other comments that you wish to make about Tidings magazine?

### Update on organisations sending ostomy products abroad

Jacob's Well Appeal is an ecumenical Christian Registered Charity supplying humanitarian aid to Eastern Europe and Asia

### Dr Beryl Beynon sent us this report:

The long hot sunny days of July were very busy for Jacob's Well. As our new office buildings were getting their final lick of paint, our admin staff and volunteers were busy moving many boxes, some filing cabinets and shelves too. The warehouse was overflowing and every day there were builders, plumbers, electricians and joiners to cope with. The computers had to be moved and, of course, all that paperwork that so bogs all of us down. Then the bills came rolling in, one after the other. I began to wonder why I had retired and thought I might be better to escape all this by going back to work as a GP!

However, August has arrived and now the heat of the move is almost over. All those ostomy bags, catheters, splints and bandages are finding new places on the shelves and the packing and listing is getting back to normal, if you can ever call this job normal! The sheer volume of it all often amazes us and as we list and cost our aid, the value of these gifts make us realise that our work is not in vain.

This summer there has been such an escalation of violence in Iraq, Afghanistan and Lebanon in particular. The hospitals are full of severely injured from roadside bombs, rockets and mine injuries. However, mainly due to political interference, it gets more and more difficult to send medical aid to where it is needed. This year our containers are struggling to get through the bureaucracy of the Afghan Government and our medicines have to go through quality control, for a charge, of course. We now have been told that there will be a restricted list of medicines that can be imported by aid workers, but if you are trading you can bring in all medicines. We have been waiting for several months

for the list of permitted items but so far none has come. It is trade not aid that is to be promoted, say the western capitalists guiding the present government.

For the poor this is very sad because there are still many patients who cannot afford to buy their medicines from the bazaar and they just stay away. There are very few Afghan patients who can afford to buy their own colostomy supplies and I can assure you that there is no hope that the Afghan Ministry of Health will be able to afford them either. We know that they will always be welcomed, providing we can continue to get our supplies through.

We would like to thank all of you who have so generously given us the supplies which you no longer need. We do know how precious they are and we will do our best to get them boxed, listed and exported to countries that need them. If you have gifts, our new office will be waiting to take your call on 01482 881162. Email: thejacobswell@aol.com

Best Wishes from Jacob's Well Appeal

### S.C.A.R (Stoma Care and Recovery) - Scotland

#### Hí folks,

You may remember reading our appeal for surplus supplies in a former edition of TIDINGS. Well we are here to say a big THANK YOU. We couldn't have imagined the amazing response we got from so many of you. It didn't take long for the parcels to come rolling in with all sorts of appliances and accessories, all of which were a great help to those fellow ostomates abroad.

We as a group have decided to send the supplies ourselves directly to Eva in Kampala, Uganda. This is because Scottish International Relief, who, when we first started the appeal, were sending the stoma appliances abroad are no longer able to do so. The same applies to a second charity we have used in the past. We don't know exactly why. Any other charity we have approached are also unwilling to help get these supplies abroad. Does ANYBODY reading this have any suggestions to overcome this problem? We would be delighted to hear from you, if you do. I know for a fact that one of the manufacturers of our appliances had agreed to pass on not just boxes, but PALATTES of boxes, if we could only find the transport to get them there.

At the present moment we find ourselves with a backlog just BEGGING to be used. We will continue to send supplies to Eva and keep a note of other individuals. However the priority for us is to find a way to reach more of our fellow ostomates, who are much less fortunate than ourselves. Your help has been truly amazing, so THANK YOU on behalf of everyone that we have been able to reach so far. I hope the next time I write I will be able to tell you that we have found another way of accessing abroad... fingers crossed.

Once again many thanks.

#### Maggie Littlejohn

Contact: maggielittlejohn@aol.com

### Tony's New Zealand Travelogue...



#### **Getting** Organised

Well before our departure date, I estimated how many pouches I would need for five weeks away and arranged with my delivery company to send my order direct to our friend's address in New Zealand. This service is free of charge and the order arrived in a week. I would also take a supply in my back-pack and a similar amount in my checked-in luggage. I'd, therefore, have two complete sets with me and the fall back of another complete set already in New Zealand. There was no problem getting a prescription for such a large order, because I explained to my doctor that I would be on holiday for over a month.

Before we left I also talked to my Stoma Nurse and she kindly gave me contact names and telephone numbers in Singapore, New Zealand and Thailand, just in case I had any problems. She gave me a signed card stating, in several languages, that I have a stoma and that the supplies I was carrying were for my own personal use. Then she reminded me to pack scissors in my checked-in luggage - scissors in hand luggage will be confiscated by security.

#### Singapore Stop-over

We set off from Heathrow for a twelve and a half hour flight to Singapore, where we spent a couple of days sightseeing and shopping. The best places to eat were the food halls in the shopping malls, which offer a wide variety of foods to sample at reasonable prices. Alcohol was very expensive but we just had to have the customary 'Singapore Sling' in Raffles Hotel. Public transport is excellent and very reasonably priced. Singapore is an exceptionally clean country and imposes heavy fines for litter.

#### Then it was on to Auckland

Another ten and a half hour flight, including a brief stopover in Sydney. In Auckland our friend was waiting and we went to the information

booth to find a hotel. The Kiwi International was close to the airport and reasonably priced. The next day we picked up our camper van, a little Fiat Ducati, adequate for two people with its own shower and toilet. Then off we went!

#### Kings of the road

The van went like a bomb and was very economical on diesel. Diesel is a must as the price of petrol is far more expensive than back home. The first night we spent at a camp, which had all the facilities you could want. The kitchens and shower facilities were clean and generally well organised; the laundry had large washing machines and dryers. There was internet access and stacks of free leaflets and maps about places of interest. We briefly touched on the North Island. as we had been told the best bits were in the South. We were not disappointed. The crossing from the North to the South Island, across the Cook Straits. was absolutely breathtaking. It is simply impossible to capture the beauty of Marlborough Sound; it is something that will stay in our minds forever.

#### The South was just amazing

Nelson is a beautiful little town, which we immediately fell in love with, and here we made our first unscheduled overnight stop. We had no knowledge of Nelson before we left, but since we have been back everyone who has been to New Zealand has asked whether we stopped there. That's the beauty of the camper-van: you can just stop wherever you want. We usually stayed at a campsite every other night so that we could top up with water and empty our waste tanks. The rest of the time we found somewhere picturesque, by a lake or in one of the many National Forests.

The weather was kind to us and we only had one day when we were Tony's New Leader Travel rained off - that was on the way to Franz Joseph Glacier, high in the beautiful Southern Alps. However, it did clear up later and we drove on to Fox's Glacier, which was spectacular. However, in the mountains it can get very cold and. although the campervan had a heater, we did find we needed a little extra clothing including woolly hats.

During our

South Island travels we picked up several hitchhikers in the form of sand flies, who are merciless and seem to love tourists! We must taste better than the natives. A Deet-based insect repellent is a must and I have heard eating marmite and taking one the B vitamins (B12, I think) is another good deterrent.

#### Queenstown, the adventure capital of the South

It was here that I abseiled across the Buller Gorge swing bridge and took a iet boat ride on the Shotover River. I jumped 43m from the Kaiwara Bridge, the first bungee site in New Zealand. I would dearly have loved to have done the other bungee jumps around Queenstown, which are much higher than Kaiwara, but unfortunately we ran out of time. Never mind there is always the next time! You have to leave something to go back for!







#### Ten days touring in the south

We got as far south as Milford Sound and Dunedin. Milford Sound is beautiful, but it did take us a hard day's driving to get there and back you can, in fact, fly direct from Queenstown, which would have saved us time. Our tour guide kept apologising because it wasn't raining - apparently Milford is well known for its wet weather. That day the sky was clear and the water calm giving us excellent photo opportunities.

We drove back up along the east coast and it was great to be able to stop off at little farm shops and buy their home grown fruit and vegetables. When we reached Christchurch, we called at another friend's house. We were glad we had followed advice to go anti-clockwise around the South Island as the most beautiful sites are on the west coast, which is very mountainous. It meant we were able to make up time on our return journey up the east coast, which doesn't really have as many places to visit unless you want to stop-over in major towns.

A highlight of the east coast was the whale watching trip in Kaikoura. We saw three whales and at one stage two of them dived together -we almost got a double fluke picture. The boat was then followed by a large pod of Dusky Dolphins which were absolutely delightful.

#### Back on North Island

The first part of the drive from Wellington was very challenging with hairpin bends for several miles. We drove along the east coast and stopped off at Lake Taupo, a lake the size of Singapore, where tourists can try out water sports or go fishing. Next was Rotorua, where tours of Maori settlements and a 'Hangi', a traditional Maori feast with dancing and entertainment, were on offer. Then it was back once more to

Auckland to drop off the van - and, of course, I couldn't resist the challenge of a sky jump from the top of the Auckland Tower - 192m! What an experience.



#### Homeward Bound

We boarded the plane for a twelve and a half hour flight to Thailand. The first two days we spent sightseeing in and around Bangkok, visiting all the major sites and sampling all forms of transport including the Tuk-tuks, whose drivers all appear to be on a suicide mission. Then off to the beach for three days or so to chill out after all our adventures. Thailand was a beautiful experience, the people were so lovely and we managed to find a local taxi driver who waited so patiently while we visited the sites - far better than going on organised tours that keep to a timetable.

#### We thoroughly enjoyed the experience and I took only a few precautions

I would reduce my food intake the day before travelling. Some people find that taking Imodium is helpful. However, before deciding on any course of action it is best check with your Doctor or Stoma Care Nurse. I also used a drainable pouch as an insurance policy. Carrying a change of underwear and an extra T-shirt in my hand luggage and keeping a set of wipes, pouches etc. with me at all times gave me extra confidence. I made sure to drink plenty of water to keep my fluid levels up.

For irrigating I used only boiled mineral water in both the camper van and in Thailand. I was quite surprised that my body clock accepted the different time zones so readily and I didn't really have any problems with irrigation. I am lucky in that I can eat most things, but if there are any foods that cause problems or wind it is best to avoid them. I also tried a pouch which has a flushable inner liner. These were quite good and are easy to use as the liner is easily disposed of down the toilet, although I did have some problems with the filter.

As with all journeys forward planning is a must but particularly so for those of us who have a stoma. If you anticipate anything which could go wrong and plan for it, inevitably it, more than likely, won't happen.

### Gay Ostomates Website...

When Brian submitted this article for publishing in Tidings, we wondered how it would be received by our "older readers". However ostomates are ostomates, regardless of colour, creed or sexual orientation. To have a website where you can ask questions, receive answers and know you are no longer alone is good for us all. When we first have a stoma, whether a colostomy, ileostomy or urostomy, we feel that we are the only person who carries this "addition to our bodies". Brian's caring attitude for all those who wish to access his website, shows us all that this is not so. The aim of the Colostomy Association is to ensure that everyone who needs it will find support in every way they can. So read on...

With a reported 100,000 ostomates in the UK, it stands to reason that there must be a substantial number that are gay, lesbian, transgender or bisexual, and very many more worldwide. Why should being gay make any difference? Well, for a start, most gay people are very image conscious and like to keep looking good. When we have surgery, we are not always with a partner who can accept things as they are. As with all ostomates, there is the problem of explaining the presence of a stoma to a potential partner.

My name is Brian and I am now in my fifties. Because I was single when I had emergency surgery for an ileostomy, I have the prospect of living on my own for the foreseeable future.

I was diagnosed with Ulcerative Colitis in 1991 and had hospital treatment after losing several stone in weight. Even then, 15 years ago, as soon as I said I was gay it was assumed that I must have HIV so I was immediately transferred from the ward to an isolation unit where I was fed on paper plates and everything I touched was thrown away. Despite my protestations that I was certain that it was not HIV, it was only when my test results were complete that I was returned to the ward. It was not a very pleasant experience, I can assure you, having nurses and visitors put on masks to talk to me.

After a few weeks treatment I recovered and was unfortunately not advised to have any check-ups, so when Ulcerative Colitis came back again 8 years later; it was so severe that I had to have an emergency total colectomy with no preparation for a stoma and all that meant. So how can a gay or lesbian person with an ostomy find out how to deal with this unwelcome newcomer? Well, after nine years, I found that on the internet there were websites for most sections of the community, but oddly there were none solely for gay ostomates. Where could someone find out how other gay people deal with getting on with their lives?

This is why, a few months ago, www.gayostomates.org was born. Of course some sites may include a mention of the word 'gay', but I discovered that there was no single website in the UK which was created just for the gay community. In fact I only found one other in the world and that was in America.

So what's so special I hear you say? Well, apart from the letters, tips, links, advice and help, there's also a chance to register - for free. This provides the opportunity to get in touch directly with other gay ostomates to exchange views via email, or, perhaps, to meet up to talk to someone, who has the same problems and issues.

When I started the Website it was primarily a way to meet other gay ostomates in my area (Manchester). My Stoma Nurse thought this would be really useful to others, so I registered a local domain name for the website, (www.gayostomatesinmanchester.co.uk). Within just a few days I had requests to do the same in London and then in Birmingham. Soon after I had people registering, not only in the UK, but from all around the world: Spain, Canada, USA, Germany...and even the Bahamas! Clearly the need

is there and, with help to meet

running costs from various medical



Brían Roberts -A caríng attítude...

suppliers, the website quickly took off.

Other organisations have provided support and encouragement. They realized that you don't have to be gay, lesbian, trans, or bisexual to find useful advice on this website. Everyone is welcome and if you expect to find anything outrageous or shocking because it is a 'gay' website then I am afraid you will be disappointed - it is 100% family friendly.

I am very grateful to the Colostomy Association for allowing us to be included in this issue of Tidings and invite all gay, lesbian, bisexual or transgender colostomates to visit our Website. It has evolved so much in the past few months to become what it is now: as the logo says – The World's Biggest Website for Gay Ostomates - www.gayostomates.org

#### By Brian Roberts



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### The CliniMed Group...

A number of people will have heard of "CliniMed", "Welland" and "SecuriCare", but won't necessarily realise that these three British companies are related, and are all part of High Wycombe-based "CliniMed Group".

he business started in 1982 with the founding of CliniMed Ltd – which was established to distribute an imported range of stoma pouches. These pouches quickly became popular, and the company thrived.

In 1988, sister company, SecuriCare (Medical) Ltd, was established to provide Stoma Care Nursing services in parts of the country that had no NHS nursing provision. Today, SecuriCare is the largest private provider of Stoma Care Nurses to the NHS, where they work as integrated members of the NHS team - as well as one of the largest "Dispensing Appliance Contractors" in the UK. SecuriCare dispenses all makes of ostomy appliance and accessory, and uses the fees that it earns from this activity to fund its nursing services. SecuriCare's head office Customer Service Team are finalists in this year's Customer Management Journal's "National Customer Service Awards" - and eagerly awaiting the Awards' presentation evening!



SecuriCare Customer Service Team at head office, one of four finalists in the pharmaceutical and healthcare sector of this year's Customer Management Journal's "National Customer Service Awards"

By 1997, "CliniMed Group", as it had become known, had aspirations to become a manufacturer of pouches, and acquired Crawleybased Welland Medical Ltd. Welland was already known as an innovative company, which had developed a particularly effective skin-protecting pouch adhesive; but what was most exciting at the time was its recent introduction of IMPACT – the world's first colostomy pouch with a toilet-flushable liner.

IMPACT quickly established itself as a favourite with many UK colostomates, and went on to be awarded top position on the Department of Trade and Industry's "Spiral of Innovation" at the Millennium Dome. Over the years, Welland has continued to develop its patented "flushable" technology for colostomates, culminating in the "FreeStyle Flushable" closed pouch. FreeStyle Flushable is the company's most successful product, both at home and abroad, bringing a new sense of freedom into many colostomates lives.



Welland now concentrates on the research, development and manufacture of high tech ostomy pouches and accessories (like the popular "HydroFrame" hydrocolloid flange extender) and relies on independent distributors to market its products around the world.

In the UK that distributor is CliniMed Ltd, which introduces Welland products to Stoma Care Nurses and patients alike. In so doing, CliniMed makes extensive use of the Patient Association journals – particularly "Tidings".

CliniMed has always realised that an effective stoma care routine involves more than just pouches, which is why it developed its "Essentials" range of ostomy accessories. CliniMed is UK market leader when it comes to deodorants, skinprotecting barrier films, adhesive removers and adhesion enhancers. You don't have to be a user of Welland pouches to enjoy the benefits that these products offer; they will complement your lifestyle



whatever pouch you choose. All the companies in the CliniMed Group have tried to "give something back" to Stoma Care Nurses and the various Patient Associations over the years. Nearly all of these initiatives have an educational theme, and range from the organisation of entire clinical courses for nurses, through to the provision of training and meeting facilities for the Colostomy Association.

On October 2nd 1993, at the first World Ostomy Day event to be held in the UK, the then CliniMed Group Chairman, Mr Dennis Piercey, gave a keynote address entitled "The Four Pillars of Wisdom". In this speech, Mr Piercey spoke of his vision of Government, Industry, Stoma Care Nurses and the Patient Associations working together to maintain the highest standards of ostomy care possible for UK patients.

Nigel Piercey Group Chairman, CliniMed Holdings Ltd.

On behalf of the Colostomy Association I would like to thank Nigel and the CliniMed Group for being the first manufacturer to take up our Platinum Sponsorship.

Sue Hatton Chairman of Trustees

# Meet Matt. He's one 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.

So whether it's a new order or a repeat prescription, Matt will get your order right. Call us. It's free, it's friendly and it's just for you. Call now for your free copy of our newsletter 'Hand in Hand'.

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Section

0800 585 125 www.securicaremedical.co.uk info@securicaremedical.co.uk

# Dear Nurse...



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

Q: I have had my colostomy since November 1991 and until recently never had a moment's problem.

However during the last six months my stoma has gradually got bigger to the extent that it now protrudes from my stomach by approximately one and a half inches. There is no pain, no irritation, no rash, but I have difficulty forcing the stoma back into my stomach when I am applying a clean pouch. Immediately the pouch is in position the stoma forces itself out again. This then seems to put pressure on the pouch, which sometimes causes a wrinkle or a gap to appear around certain parts of the flange, causing a leakage. In most instances the moisture leaking out is mucus, slightly stained by faeces from inside the bag. This problem is becoming more and more frequent and I never know where or when it may happen.

I have tried various different pouches recently without success. My motions are perfectly normal. I am a perfectly fit eighty-five year old and do not suffer from any disability, therefore am not on any form of medication. Should I see a consultant or do you think I should leave well alone? Your opinion would be very much appreciated as these leakages are worrying.

A: This may be a small hernia or a prolapse, neither of which should require surgical intervention unless they cause severe problems. It may be worth a review by your Stoma Care Nurse who can advise you on different pouches and possibly an abdominal support to help with the swelling, especially if it is a parastomal hernia. A pouch which cuts to a larger size may help to solve the leakage problems or possibly a special hernia pouch, available from a few manufacturers.

Q: My father had surgery for rectal cancer in 1987. His rectum and anus were removed and he has a colostomy. Since that time he has suffered intense pain at and around the site of his "one-time anus". He describes the pain as "like a red hot spike being moved in and out" Applying pressure at the site gives him some relief.

At first he was told it was "phantom pain". Can this be so after nearly 20 years? He has tried all kinds of medication, spinal nerve blocks, and has attended pain clinics. He has even undergone surgery - the thinking being that the small bowel had torn and was pressing on the site. However none of these measures have provided any relief whatsoever.

Do other colostomates suffer from this condition and can you suggest a new approach?

My father would also welcome any response from other readers, who are experiencing a similar pain.

A: I have several patients who tell me about similar experiences with 'rectal' pain. This can be due to phantom pains, but can also be due to a physical problem, such as a perineal hernia. Many patients manage the symptoms through the use of pain relievers, nerve blocks and treatment from the specialist pain clinics. However a few have required surgery to repair a perineal hernia and have found this has solved the problem. Obviously without a physical examination it is difficult to assess the actual cause of the problem, so I would suggest a review by your Stoma Care Nurse in the first instance, then possibly by a Consultant Surgeon, who can assess if it is a hernia and advise regarding a treatment plan.

# Q: I am fifty one, have had my colostomy for six months and am adjusting well.

I am concerned however about developing a parastomal hernia. Can you advise me on what activities, if any, may cause them, or do they occur for no apparent reason? My stoma nurse has suggested I

My stoma nurse has suggested I wear a "girdle", but I am slim and active and find a "bag" enough to cope with at the moment.

A: Parastomal hernias are very common and can occur for lots of reasons. Some people find that doing something which causes a strain on their abdominal muscles, such as heavy lifting, can lead to herniation, especially in the early days after surgery when the muscles are still weak. However many people, especially those who are very active and who re-introduce their normal activities slowly, find they do not have a problem. If you are concerned I would agree with your Stoma Care Nurse and suggest an abdominal support. This need not be a very bulky appliance: you can now get very lightweight supports, and you may only feel you need to wear it when you are exercising or lifting. It may be worth having a discussion with your Stoma Care Nurse again and asking to look at some of the lighter weight appliances available. You are not committing to having one, but you may find they are not as bad as you think ..



### From our Readers...Hints, Tips and Gadgets...

#### Dear Edítor,

I hope this letter will be of some help to my fellow colostomates, who have a similar problem.

Just after my 70th birthday last September, I was diagnosed with cancer of the colon. Other health problems: spondilitis of the neck, diabetes and being on warfarin, made it more difficult for the surgical team. However I had my colostomy operation in February this year and everything went very well. In fact I was only in hospital for ten days with no follow-up chemotherapy.



The only problem I have is that, due to my lack of neck movement and being on the large side, my stoma site is out of sight without the use of a mirror. As we all know, not all public toilets have mirrors. So, to get over this problem, I always carry an adapted six inch diameter mirror, to which I have attached a length of string and an L shaped bracket. I place the bracket over the top of the open toilet door then close it thus trapping the bracket in the door frame. By adjusting the string length I can now see my stoma to make changing the bag easy. I have enclosed photos to make it easier to understand.

I would like to take this opportunity to thank my surgeon, Mr Lees and my stoma care nurse, Mandy Smith and all the team at Hope Hospital Manchester, not forgetting my wife, Norma, and all my family, who must have had a more difficult time than I had.

#### Your faithfully, Mr Brian James Hayes

Thank you Mr Hayes. An ingenious solution to a problem ostomates may encounter, particularly when staying in hotels, when the mirror in the bathroom is not at the right height. Ed

#### Light fantastic...

When a carer is fitting a colostomy bag to a patient, adequate lighting of the work area can be an important factor.

Recently we learned of a technique used by a gentleman who is the carer for his wife.

The gentleman has various interests and, in relation to working with personal computer circuit boards, he bought from the QVC shopping panel a head-mounted light, such that when someone is working on intricate items, a beam of light directed at the place at which the wearer is facing is always available, automatically, as the light beam moves as the wearer moves his or her head.

When the light unit arrived and the gentleman was showing his wife what he had bought, the lady remarked that it would also be of use when he was attending to her stoma.

This has indeed been the case and the light unit has been very useful in this regard. The carer states "The unit gives a white light and its position on the forehead does not cast any shadows. This is much better than room lighting or extended arm lighting which give shadows and a slightly yellow light. I saw the stoma in a new light."

The light unit is available from QVC, the television shopping channel.

To contact QVC, telephone 0800 51 41 31 or visit www.qvc.co.uk for enquiries and, if you so wish, purchases.

If you have any hints and tips you would like to share with other readers, please ring our Helpline or write and tell us about them...

#### Tips from members at the Nottingham Support Group

Peter explained why he always keeps a small retractable radio aerial with the "spares" he carries with him wherever he goes. He uses toilet disposable colostomy bags and occasionally they don't flush away at the first attempt. With the aerial extended he is able to give the flushable liner a nudge to help it on its way round the U bend. A good wash and it's ready for the next time it's required. It comes in very handy when away from home and he doesn't want to keep repeatedly "pulling the chain".

Sylvia uses a two piece appliance. To prevent any leakage, she likes to be sure that the base-plate adhesive immediately around the stoma (inside the plastic circle which clips to the bag) is firmly stuck down. This space between stoma and the circular clip is too narrow to check with a finger, so she uses a cotton bud to ensure a good seal between the flange and the skin.

#### And Remember...

Clothes pegs can be useful for keeping clothes out of the way while changing your bag. Tie one on each end of a cord and hang it round your neck.

### From Mouth to Stoma...

'How long does it take food to pass through the system?' The answer usually begins with the words, 'Well it depends ...' This article describes what happens to food once you've swallowed it, and the changes that take place en-route to your colostomy.

Most of the time we are unaware of food as it progresses along the digestive tract. This is governed by the automatic action of nerves and muscle in the wall of this very long tube, which extends from mouth to anus. or in our case a stoma. The diagram shows how this tube changes in shape and coils around, but you will appreciate it is very much simplified and other body parts like the liver, bladder and reproductive organs, which also occupy space in the abdomen, are not shown.

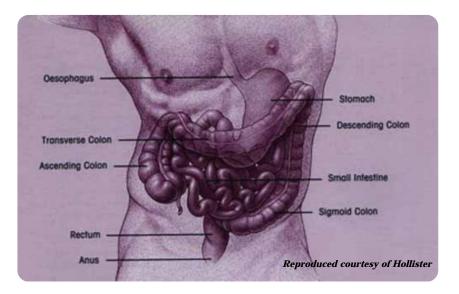
Once food has been swallowed, it passes straight down into the stomach. Here it stays for between two to five hours. During this time, it is churned around and broken down into smaller particles and the process of digestion begins. By the time food leaves the stomach and passes into the small intestine, it is the consistency of thick soup.

The small intestine is about fifteen feet long and coiled around, so that it fits compactly into the relatively small space available in the abdomen. Muscles in the wall of this tube squeeze, stir and propel its contents onwards. Here digestion continues. Bile enters, from the liver via the gall bladder, to disperse fat into minute droplets. Substances called enzymes ooze out from the pancreas and the wall of the intestine. With the aid of these enzymes, nutrients in our food are broken down into their simplest components. Protein into amino acids, fats into fatty acids, and carbohydrate into simple sugars, mainly glucose.

The lining of the small intestine is folded and ridged and has tiny hair like projections called villi. This provides a very large surface area, through which the digested nutrients can pass, on their way into the thousands of blood capillaries in the wall of the intestine. The nutrients then pass, via the blood, to all the tissues and organs of the body. Here amino acids are reformed into human proteins and simple sugars and fatty acids are used to produce energy or stored as fat for future use.

Because of all the changes that have taken place, it is difficult to say, how long food remains in the small intestine. Some textbooks say four hours, but this varies, both from person to person and in the same individual from one day to the next.

The final part of the small intestine (or ileum) joins the large intestine (or colon) on the lower right hand side of the abdomen, where we find our appendix. If for some reason the whole of the



colon has to be bypassed or removed, then the ileum can be brought to the surface at this point to form a stoma. This called an ileostomy. Fortunately all the nutrients we need can be absorbed before food reaches the colon. Water, however, is mainly absorbed in the colon, so the output from an ileostomy tends to be fairly liquid or like toothpaste and be produced fairly constantly. This is why most ileostomists use a drainable bag.

But for those of us with a colostomy the story goes on. What remains, when food reaches the colon, is fibre and other indigestible matter such as some carbohydrates found in peas and beans and unripe bananas. Also other substances like bile and worn out cells shed from the gut lining, together with a large amount of water. The colon's main job is to absorb salts and water making the contents more solid. It is also the home of billions of bacteria. Most of these so called "friendly bacteria" are harmless and may even be beneficial to health. Their job is to ferment the parts of our food which has so far escaped digestion. This process also produces gas, a reason we all, now and again, suffer from wind!

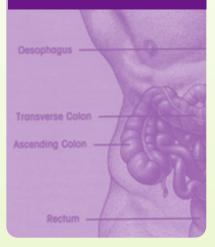
The colon is about five feet long and much wider than the small intestine. It consists of the ascending colon which travels up the right hand side, the transverse colon which crosses the abdomen and the descending colon down the left hand side. Movement around the colon is much slower and is also stimulated by food entering the stomach, which explains why a stoma frequently works after meals. To travel the length of the colon can take anything up to forty eight hours, but obviously this varies from one person to another and will depend on how much of the colon remains. If the colostomy is formed in the ascending colon, the time will be much shorter, less liquid will be absorbed and the output similar to an ileostomy. If your stoma is in the descending colon, then what remains of your food will have travelled almost as far as it did before your surgery and the consistency of the output will be more solid and the pattern of emptying less frequent.

So the contents of your colostomy bag are not only the remains of what you ate yesterday or perhaps the day before that, but also cells shed from the gut lining, bile, mucus and other secretions and the bacteria which thrive in the colon. The process described here may be familiar to many people reading this article, but hopefully it explains why there are not always simple straight forward answers. It can take anywhere between one and three days for food to pass from mouth to stoma and what you've eaten is completely transformed on the way.

Reprinted from Tidings Issue No. 5 July 2000

> "Most of the time we are unaware of food as it progresses along the digestive tract. This is governed by the automatic action of nerves and muscle in the wall of this very long tube, which extends from mouth to anus, or in our case a stoma".

#### Mouth to Stoma...



# Did you know that many Ostomate Associations abroad are willing to help visitors?

Many ostomates are concerned about travelling abroad, lost luggage being a major cause. There are ostomates all over the world and most countries have associations or support groups willing to help visitors. It is worthwhile having the contact details with you of the country you are visiting. The International Ostomy Association (IOA) gives information on associations worldwide, details can be found at www.ostomyinternational.org.

We have listed popular destinations and their support. Please contact us if you have any concerns with travel.

#### Australía

Australia has Ostomy Support Associations in all seven states. They are all contactable by phone or email. These are obtainable on the Australian website www.australianstoma.com.au. If you do not have access to the internet and are travelling to oz please contact the office in Reading for more information.

Visitors may, at the discretion of an individual Association, purchase supplies from that Association at a price determined by that Association.

*Note:* The range of ostomy products held in stock by individual Associations varies and visitors should, if at all possible, provide advance notice of any supplies required. Also Australia does not stock all the same appliances that are available overseas but an alternative can be found provided advance notice is given.

New Zealand Federation of New Zealand Ostomy Societies Contact: Robyn Tourell FNZOS Secretary 98 Highcliff Road Dunedin 9013 New Zealand Tel 64 3 454 5330

#### Spain

Expatriate Ostomates of Spain (EOS) Contact: Cynthia Robinson National office: 0034 96 6146 0063 Email: OSTEXT@terra.es or mail@ostomyinspain.org Web: www.ostomyinspain.org 'Dedicated to the support and representation of all expatriates and their carers living in Spain. Also will assist visitors and Spanish nationals.'

#### USA

The United Ostomy Associations of America (UOAA) is made up of many associations in different states. The central office has a toll free number for calling within the US: 1.800.826.0826 and is usually manned 8-4.30 central time. The office administrator is Joan McGorry, who will be happy to help visitors to the US.

When travelling abroad it is a good idea to spread your stoma supplies throughout your luggage in case of loss. And remember aerosol sprays and scissors are not allowed in hand luggage.

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

(FREESTYLE\* USER)

Does it often feel like your stoma is ruling your life? If so, you're not alone. A recent report found that many colostomates restrict social and leisure activities because they are concerned about changing and disposing of their pouches.'

But now, with FreeStyle" Flushable, this no longer needs to be the case.

FreeStyle\* Flushable has an inner liner that is easily removed and flushed down the toilet. What's more, the unique filter system deals

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I. Pouch change & disposal study. C White PhD. Presented at WCET Conference, Braal 2004.

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Flushable, you can enjoy much more freedom in your life.

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#### Spotlight

### Support Group in the Spotlight Bishop Auckland Ostomy Group

Mrs Maureen Davison wrote to tell us that the Bishop Auckland Ostomy Group is celebrating their twenty-first anniversary this year - twenty-one years of friendship and dedication.





#### The group was formed by our Stoma Nurse at the time, Barbara Hodgson, together with Betty Towns, Vera Bradford and George Suddock. We have over fifty members now and have been told by the reps from the stoma companies, who attend our meetings, that we are the largest group in the North. We meet every fortnight, on a Thursday; we have raffles and entertainment, plus tea and quizzes. We even had a belly dancer one Christmas!

Over the years we have had bus trips and even an overnight stay in the Lakes and Harrogate. We're a very active group, and have put posters up in Doctors surgeries and have visited patients in hospital when needed. Our nurse, who has since married and retired, won a competition in 1999; she came third in Angel of the North and won £500 of holiday vouchers. A few years later Barbara even went down to London with our eldest member, Vera Bradford (now 93) to receive an award from Prince Charles for her dedicated work in Stoma Care.

We would like everyone to know about our group. This Christmas will be extra special, twenty one years is a long time!

#### FAMILY

I have another family I would like you all to know Where I can go and have a talk When I am feeling low It's the Stoma Club from Bishop Auckland Where my many friends go And I've been very busy, as you will see When I tell you what the Club and Nurse mean to me We have a nurse called Barbara And we love her so And I wrote a poem about her Not so long ago We love you Barbara Through and through For all the good work that you do Our lives would be empty without a doubt If we didn't have you to sort things out What would we say? What would we do? If we hadn't met a nurse like you The Lord of the Angels from up above Must have sent you with his love You may think life's over when you've had the 'Op' And your mind's all full of doubt But when you meet friends like us We can help you sort things out We meet every two weeks And have trips during the year Have nice cups of tea and cakes and raffles galore Oh, and Santa Claus was also good you know The Reps are good and charming and help us through If we have a problem they soon tell us what to do The quizzes are good; you get such a laugh And there's plenty of food If you are lucky and win the Quiz You may win a bottle of Fizz

Maureen

Thank you for telling us about your group Maureen. We are considering making 'Support Group in the Spotlight' a regular feature in Tidings.

If you would like to be included, do write and let us know about your group: have you recently celebrated a special occasion or had a visit from an interesting speaker? Would you like to tell readers about an event you have planned for the future? Ed.

### Drop in on your local Support Group

#### Wales

#### Wrexham

Wrexham Ostomy Friendship Group Mineworkers Institute, Grovenor Road

#### Meets:

Every month, Tuesdays: 7.30pm *Contact:* Mrs R Thomas 01978-359445

#### Swansea

Swansea Ostomy Self Help St. Pauls Church Hall, Sketty Meets: Most months, call for details Contact: Glynis Jenkins 01792 418245

#### Ireland

#### Craigavon

*Craigavon Hospital* 68, Lurgan Road, Portadown *Meets:* Twice a year – usually April or May & October or September *Contact:* Mary Jo Thompson or Bernie Taylor 0283 8334444

#### Coleraíne

Causeway Patient Support Group Meets: Every three months - 2nd Thursday (March, June, September, December) Contact: Mary Keane 0287 0346264

#### Belfast

Outlet Royal Victoria Hospital Meets: Four times a year Contact: 02890633483 (answerphone)

#### England

#### East Anglía (West)

Stars Various Venues Meets: Every 3 months, Sun 2pm - 5pm Contact: Judith Franks 01953 452484

#### Leicester

Moving on (Leicester Royal Infirmary Colorectal support Group) Clinic 2, Balmoral Building, Leicester Royal Infirmary Meets: 3rd Saturday of every month 11am-12pm Contact: Wilf Patterson (Secretary) 01455 220344

#### Ashford, Kent

Ashford Stoma Support Celia Blackey Centre, William Harvey Hospital *Meets:* Every month Mondays 7.30pm *Contact:* Ursula Nish 01233 640863 Julie Bell 01233 616646

#### Bíshop Auckland, Durham South West Durham

Ostomy Group Escombe Road Health Centre Meets: Every fortnight Thursday 1pm Contact: Maureen Davison 01388 818267 Brian 01388 763684

#### Scotland

#### Glasgow

*Fittleworth Support Group* Unit 1,Riverside Business Park, 45 Moffatt Street *Meets:* 1st Tuesday of every month *Contact:* Maureen Anderson (SCN) 0800-7837148 (Home baking/coffee/speakers)

#### Livingston

GOSH St Johns Hospital, Howden Meets: Every month, Wednesdays 7.30pm Contact: Alec Topping 01501 772154

### Starting up a Support Group...

Starting up a support group can be daunting, especially if you have never done anything like it before.

- Where do you find your members?
- Who do you ask to come along?
- What sort of group should it be?
- How many times will you hold a meeting?

S etting up a Support Group brings many exciting challenges. Because I am drawing on the experiences and views of myself and others, I hope that this article will help you decide to go forward! It can be very demanding on your time and energy, but the results are so rewarding.

The whole point of setting up a support group is to offer support by providing regular meetings where people can talk together in a supportive way. Having clear aims and objectives will give the group credibility, which can help relationships with the professionals.

### What can a support group offer?

Having a colostomy can turn someone's world upside down. As well as dealing with the effects of the condition, we need to be able to meet others who "Live with a Colostomy".

The difficulty of having a stoma is that it is a very private matter and some colostomates are unwilling to tell others how they are feeling. A support group can offer a safe and confidential environment where members can talk openly about their problems and express their doubts and concerns to others who have had similar experiences.

If you know your Stoma Care Nurse well, it would be a good start to discuss with her the idea of your group and what you hope to achieve. She may be able to suggest the way forward and how she feels new and old colostomates would benefit. Place well worded posters in doctor's surgeries and supermarkets anywhere that the general public will see it. The poster will need to include times of the meetings, how regular they are going to be and the decided location.

#### When you are looking for somewhere for your members to meet, bear in mind:-

- How many people do you expect to attend? It is worth while trying to determine, in advance, how many people would be interested. Your group could include ileostomates and urostomates as well as colostomates. Many members like to bring family, carers and friends.
- Is the location convenient and welcoming for new members?
- Is your meeting place safe and easy to reach?
- Are there tea and coffee making facilities?
- Will you hold meetings in your own home and look for a larger venue when you have established the group?
- What will you call your group? You will need a name to publicise your group to potential members and health professionals who will hopefully tell their contacts about you.

#### Points to remember:-

Investigate the possibility of your local hospital or community centre offering a room free of charge? Contact your local Borough Council Voluntary Action Group, who will offer advice on setting up a group in the area.

Once the principles of your group are established, decide whether you will make it a "cuppa and chat" kind of group or a structured group with visits from Stoma Care Nurses, who will give talks and answer questions. Will you invite Manufacturers and Delivery Companies along to exhibit their stoma products? If you invite speakers, you will need to check whether they need screens, projectors or audio equipment or will they bring and use their own?

Set out a list of your intentions and be realistic. With my own group I asked my Stoma Nurse if she could use her database to tell her patients about my group. I also wrote a letter telling of the time and location of the meeting and asked my supply company to forward the letters to addresses on their database. I paid for the postage but later found that the Company was willing to sponsor me, as they were willing to help Ostomates in my area in any way they could. (It is worth asking your supply company for help).

Do not be too disappointed if the group is not an immediate success and the numbers of attendees varies with each meeting. Just be aware that those that do come into the group should receive the warmest of greetings and the fellowship of members. Don't feel that your group has to take on anything specific. A successful group is based on enthusiasm and commitment by you and your members. A good goal to achieve is a happy and consistent approach to helping others into the way of thinking that they will never again feel alone with their stoma.

Asking members what motivated them to come along to your meeting may also help with identifying suitable roles for them in the group. Try to share the workload as much as possible from the very start. Some people are more than willing to take on small, one-off tasks but to take on the responsibility for the larger workload can prove more difficult as time progresses.

It is so rewarding to take on the idea of a support group - everyone benefits. I started up my support group because I didn't want others to experience the isolation that I felt once I had received my stoma. After almost a year, I gained support from attending a coffee morning - held by a Manufacturer - and was astounded by the information I received as part of a "chat" with others there. That made me determined to offer the same support to ostomates in my area. With the help and support of my Stoma Care Nurse I began the task of establishing contact with people who could help me establish the "Monday Pop-In Group" at Martins Heron in Berkshire.

I have chosen to run mine every Monday afternoon – between 2.00 and 4.00pm. at the local community centre. I was lucky and receive the room free. It has all the facilities we need, coffee and tea making items, good toilets and easy access. Members travel from the surrounding areas and numbers can vary - as few as two and as many as twenty-four! A visit from a Stoma Care Nurse or a special speaker is always well advertised in advance and the numbers increase accordingly.

A key ingredient to a successful group meeting is to respect what others are thinking and ensure that they all have a voice to state their opinions. So much help is gained when there are open and full discussions on every subject – ranging from "changing the world governments" to how you feel about a certain product!

The main aim of a support group is that the new and old Ostomate never again feel that they are on their own.

There is a check list that is useful -

- Devote time to welcoming people
- Get to know each other
- Assess what has brought all these people together and what experiences they will share
- Clarify the common values of the group
- Ensure that there is good communication between the members
- Try to give your meetings some structure
- Pay attention to the group's image and see whether it really does include everyone the group aims to reach. (ostomates include colostomates, ileostomates and urostomates plus internal pouch users – in fact anyone who has a stoma)
- Work out who could (in the event of your absence) take on key roles for the group
- Ask the Colostomy Association for literature that you can display. There are leaflets on all subjects and the Association will be delighted to advise you what is available.

Don't feel that your setting up the group has to cover everything and become everything to everyone. That will take time!!! Just be sure that you and your members are happy with the time and effort put into establishing a happy and well run group. In the early days, it is likely that you will need to concentrate on making sure that you are offering good support to your members. You will need to establish the limits you wish to set on the support you offer. Once you have considered all the options and the practical implications of setting up a support group, you should have a clearer idea of what is involved and whether you wish to go ahead with the support group.

If you decide that starting something new is too large a commitment for you at the moment, that's fine: it is much better to make this decision now than further down the line when you have expended time and energy. You can always revisit the idea once you feel more confident.

If, however, you are happy to take things further you should now have a reasonable idea of what form your support group should take.

We do have a number of members who are happy for you to contact them. They too will advise you about the setting up of support groups. Please contact us and we will be delighted to forward your details to them so that they can contact you direct.

Running a support group- however small or large- is such a worthwhile and satisfying venture. The difference you can make is enormous. We need to let ostomates know that they need never think that they are the only one ever again!

**Jackie** 



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

### Readers Writes

#### Dear Editor

I have sent this letter to tell you all how much I appreciated the help and advice given me since I had my colostomy. This came about because of having bowel cancer and without the encouragement of my colostomy "friend" things might have been so different. She was so good at listening and the advice given made all the difference for me.

I was told by my surgeon that the colostomy was not going to be reversible, but almost three years later I had to change my surgeon and he told me he would try and do the reversal operation. I was given an ileostomy at this time and have now had it removed with a good result. Everything is now back to normal.

Once again, my many thanks go to you all. You do a fantastic job.

Yours sincerely M.F.

#### Dear Editor

Since I got my summer issue of Tidings, I have read it numerous times. Anytime I feel low I go through it and feel I am not alone.

I am 71yrs old. I had cancer of the rectum and an ileostomy in January 2004. I then had chemotherapy and radiotherapy and the following October had a reversal, which was not a success. I had a miserable nine months – most of it in the bathroom!

I also had a lot of pain from radiation burns and piles, which had to be operated on. Eventually in September 2005, I had a colostomy and have been making good progress since. My weight has gone up from 6st. 4lbs. to 8st. 4lbs. I am planning my first holiday to Italy in September.

Good luck with your magazine. I look forward to the next edition.

Yours sincerely A.R.

Our new travel certificates with translations into fifteen different languages are now available. Ed.

#### Dear Editor

What a wonderful magazine. I had my stoma in 1999 and have been enjoying life and travel on the high seas. But this year I discovered the insurance companies had "cracked down" on over seventies and cancer, especially colostomies, but you know all this. Then your magazine arrives as I am tearing my hair out trying to get insurance cover. And yes, after many calls, I have now found a company quoting a reasonable price, so I can continue my cruising.

My mantra is "Better a bag than a box". Also laugh, laugh, laugh, laugh. I live alone, but am never lonely.

Kínd Regards S.O.

#### Dear Editor

I have found your Tidings magazine extremely helpful and it was nice to see your strawberry recipe in the summer 2006 edition, but I wonder if other ostomates have the same problem as myself – pips.

Since I was operated on for bowel cancer in October 2005, I have discovered that any seeds/pips from such fruits as strawberries, raspberries, red/blackcurrants, blackberries, gooseberries etc. are not broken down in the digestive system and even the tiniest pip can cause discomfort and problems for the stoma.

Could you recommend any tasty seedless strawberry plants that can be grown in the garden. Although the strawberries which we currently grow never caused any problems in the past, I now have to peel them to remove all signs of the seeds – which can be difficult and tedious! Obviously, if you could also recommend other 'seedless' fruits which would probably assist anyone with similar medical problems, it would be most appreciated. You could possibly include it as an article which could be of assistance to other ostomates.

Yours sincerely P.R.

We included this recipe in the last edition of Tidings because many colostomates can eat strawberries as the pips are so small they pass through the system with no problem. However some people do say they contribute to diarrhoea. As far as we know there is no seedless variety of strawberries - but maybe one of our readers knows different. If so, do write in and tell us. Fruit that is ripe, soft and sweet is easier to digest. Canned or stewed fruit is another option and bananas tend to be popular with colostomates - some say ripe bananas can help to thicken stomal output. We will certainly consider your

suggestion about an article on food in future issues of Tidings Ed.

#### Dear Editor

I get my supplies from a delivery company who cut the flanges to the correct size. They inform me that, due to financial cutbacks in the NHS, there may be changes to this service. This is a life-line to me and I guess there are other folks who like me have difficulty in cutting correctly, especially if they have other medical problems.

#### Yours faithfully L.D.

NHS proposals have not yet been introduced, but if they are, contact the CA and we will forward the names of supply companies still operating this service. Ed.

#### Dear Editor

As I am a very green conscious person, I was concerned about the amount of plastic I was using, even before my colostomy. I was intrigued therefore by the letter from J Forbes in the summer edition of Tidings describing the way she washes used bags, dries them and then reuses them. I had no idea that the glue would work for a second time.

As I irrigate every three days, I wash the sleeve carefully and hang it up to dry before using it a second time. I also wear my mini stoma cover for two days, not only to reduce plastic waste, but also in a tiny bid to save the NHS some money. It won't be long, I fear, before we have a different health system and not a generous one.

#### Yours H.C.

The adhesive on a one piece or two piece "stick on" appliance is unlikely to be reliable if the bag has been washed and is then reused. I suspect that the lady who wrote the letter in the last issue of Tidings is using a two piece system where the bag clips to the flange. However the **Colostomy Association believes** that ostomates should be entitled to use sufficient bags to allow them to handle their colostomy in a way that suits them best and enables them to maintain their self esteem and personal hygiene standards. Ed.

#### Dear Editor

Having had a colostomy for six years, I have only just discovered that Waverley Borough Council operate a Collection for Clinical Waste. I now place my used pouches in a separate yellow sack (supplied by the council) which I keep apart from my dustbins. These sacks are collected weekly (unlike my other rubbish which is now collected fortnightly) and incinerated at the hospital'

I have no knowledge of other local authorities operating this service, but feel this should be a National Service, because of the health hazard when the normal means of rubbish disposal is landfill. It is worth contacting your local council to enquire if they run a similar service. Also in a recent issue of Tidings you asked for a solution to eliminate smells in the bathroom and toilet when changing a pouch. Keep a box of matches and a candle in the room and light one for a minute. This will burn off the gases emitted. But be careful where you put the candle!

#### Yours sincerely G.N.

In a survey carried out by BCA in 2003, 7% of colostomates said they used the clinical waste service. We have had a number of enquiries recently from members who normally dispose of their appliances in the household waste, but are concerned because their dustbin collection is being reduced from weekly to fortnightly. We have therefore included an article on the subject in this edition of Tidings and would be pleased to receive reader's comments. Ed.

#### Dear Editor

Thank you so much for a wonderful magazine – a true friend dropping in. I am 80 yrs old, have had a colostomy for fifteen years, and have never met or spoken to anyone with a stoma. Reading the letters and features make me realise that I am not the only person in the world with a colostomy. So thank you again.

Looking forward to my next Tidings M. R.

If ever you would like to talk to someone else with a colostomy, ring our freephone numbers (0800 5876744 or 0800 3284257). We can put you in touch with someone else who also has a stoma or give you the details of a local support group. In the evenings and at weekends when the office is closed, our helpline is manned by volunteers who all have a colostomy themselves. Ed.

### **Readers** Writes

#### Dear All...

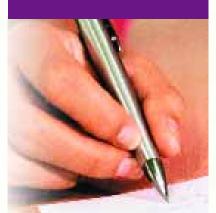
Thank you for your letters. Please keep them comíng.

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

In our next issue we will be including articles on irrigation.

Do write to us with any questions you may have or to tell us of your experiences. You may always have irrigated or you may have tried and decided not to continue. We would like to hear all your views.

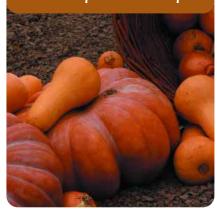
Ed



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

#### Autumnal Delights · Autumnal Delights · Autumnal Delights

#### Tomato and Pumpkin Soup



#### Ingredients:

2 tbsp olive oil 1 pumpkin, peeled, de-seeded and diced 1 garlic clove, peeled and crushed 2 tomatoes, chopped 350ml/12fl oz chicken stock 3 tbsp fresh basil, chopped

#### Method:

1. Heat the oil in a medium pan.

2. Add the pumpkin and garlic and sauté for three mins.

3. Add the tomatoes and sauté for two míns.

4. Pour in the stock and leave to simmer for 10-12 mins.

5. Drop in the basil and then remove the pan from the heat.

 Ladle the soup into bowls and serve.

### Tasty Toffee Apples



#### Ingredients:

3 Cox's Apples, Peeled, cored and sliced 20z of Butter 4tbsp of Brown sugar 1fl oz Double cream

#### Method:

1.Put the butter and sugar in a shallow pan.

2.Heat gently until the butter has melted and has combined with the sugar.

3.Add the apples and cook for 10 mins or until the apples soften.

4.Pour in the Double cream and simmer for a further 3 mins.

5.Remove the pan from the heat and pour into a serving dish.

#### Hot Chocolate with Marshmallows



#### Ingredients:

2 tbsp. Cocoa powder 2 tbsp. Mílk <sup>1</sup>/<sub>4</sub> pint of Single Cream 18fl oz Milk Marshmallows (as líttle or as many as you like)

#### Method:

1.Mix 2 tbsp. of cocoa powder with 2 tbsp. of Milk and blend into a paste.

2.On a low heat, bring the cream to just below boiling.

3.Remove from the heat and add the milk; bring to the boil whisking occasionally.

4.Fold in the cocoa paste and whisk.

5.Divide the hot chocolate between a few friends and add the marshmallows.

Recipes from BBC foods

### Have you cancelled your STANDING ORDER to the BCA?...

### If you are NOT sure...

- Please contact your bank immediately to change your standing order donation to the Colostomy Association.
- Donations currently being sent to the BCA will no longer be transferable to the CA.

GANCELLEL

colostomy

association

• We appreciate your continued support and help with this matter - thank you.



### Notice Board

#### Change of Venue for the 'Optimists'

The 'Optimists' will be meeting at the Carlton Hotel in Truro for the Monday meetings on 2nd October and 6th November at 2pm. The meeting in December will be in Threemilestone.

#### For further details contact: Sue Hatton on 01326 340058

If anyone enjoyed the article on RJ Mitchell in the Summer Issue 2 of Tidings...then read on. A book written by his son Dr Gordon Mitchell is now available in paperback from bookshops or direct. from Tempus Publishing Limited

#### Did you know...

Anyone who claims incapacity benefit is entitled to a Railcard which then gives you a 34% saving on railfares. Devon ia Serving Devon and South Somerset Pre Christmas Meeting

Date: Saturday 25th November Time: 12 noon Venue: The Community Hall, Rydon Road, Kingsteignton, Newton Abbot

### Anyone with a stoma is welcome to attend

For more information contact: Secretary - Margaret Bond on 01392 44 73 74 or email: Bomarg10@aol.com

#### Open Day...

Barbara Brown, the stoma care nurse specialist at Treliske Hospital, Cornwall will be running Open Days

Date:Wednesday 15th November Time:12Noon-4pm Venue: Kingsley Village, Fraddon

Apologies... In the Summer Issue 2 of Tidings there was a printing error in the article 'Women have handbags so what do men do? The phone number should read 01373 473217. Apologies for any inconvenience caused.

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

We hope you have enjoyed this edition of Tidings and look forward to bringing you the next edition...

#### 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.



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

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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